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## "Supportive Services for Persons With AIDS/ARC in California: Needs, Availability and Organization"

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SENATOR DAVID ROBERTI  
President pro Tempore

**“Supportive Services for Persons  
With AIDS/ARC in California:  
Needs, Availability and Organization”**

Prepared for  
The Office of AIDS  
California Department of Health Services  
By: Paul Harder, Project Director  
Alan Pardini  
Sandra Wexler

June 1987  
Conducted under Department of Health Services  
Contract No. 85-87156

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## GOLDEN GATE UNIVERSITY

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## CHAPTER ONE

### INTRODUCTION

In 1981, two unusual cases of pneumocystis carinii pneumonia from Los Angeles were reported to the Centers for Disease Control. The symptoms involved in those cases are now commonly referred to as Acquired Immune Deficiency Syndrome (AIDS). Since those first California diagnoses, AIDS has become the most pressing public health crisis of this century for the state and the nation. The number of people in California affected by the epidemic is unknown. However, over 7,500 people in California have been diagnosed with AIDS as of April 1987. Of these, 55% already have died. While there are no definite statistics on the number of people suffering from the other major set of symptoms associated with HIV (Human Immunodeficiency Virus) infection, AIDS Related Complex (ARC), estimates suggest that as many as an additional 35,000 may manifest ARC. Over 50,000 of these individuals will be diagnosed with AIDS. By 1991, AIDS will have caused over 34,000 deaths in the state.

The size of the infected and diagnosed population, the rapid rate with which the infection has spread and intensity of required treatment have created a crisis in the state's system of human services. To date, hospitals (primarily county-operated) have borne the brunt of serving people suffering from AIDS or ARC. As the size of the infected population has grown and our experience in treating the various forms of HIV infection has deepened, there has been increased interest in the impact of the epidemic on the broader range of California's human service institutions. These institutions, community-based and public agencies, are finding themselves increasingly involved in responding to the continuing care needs of persons with AIDS and persons with ARC (PWAs/PWARCs). With the continuing development of promising new treatment approaches, there are likely to be dramatic changes in the survival rates and lengths of time in treatment for PWAs/PWARCs. Until now, there has been no systematic effort to understand the service needs of the infected population outside of the health care system or the impact of the epidemic on the broad array of community service providers.

For these reasons, section 199.71(a)(8) of SB 1251 required that the Office of AIDS of the California Department of Health Services conduct a statewide "needs assessment of

the availability of supportive services for people with AIDS and AIDS-related conditions." The URSA Institute, a nonprofit research organization in San Francisco, was selected by the Office to conduct this study in conjunction with the evaluation of AIDS community education efforts that the URSA Institute was also conducting for the Office.

This report presents the URSA Institute's analysis of the supportive service needs of people who have been diagnosed with AIDS or ARC in the state of California. As used in this report, the term supportive services include all formal and informal services used by PWAs/PWARCs outside of acute health care. A more specific definition is presented in the body of the report. The report contains descriptions of the supportive service needs of PWAs/PWARCs, the response of local service systems to those needs and organizational issues faced by public and private (nonprofit and for-profit) service providers around the state. The nature, level and type of service needs (met and unmet) are discussed. An analysis of the actual organization of services in selected counties is followed by a description of a recommended model of county-level service organization and delivery. The report concludes with recommendations for services which should be expanded and/or created to meet the needs of PWAs/PWARCs.

## SCOPE OF THE STUDY

The legislative mandate for this project was broad. One of the first research tasks was to articulate the specific questions to be addressed. The URSA Institute team and Office of AIDS staff met several times to refine the scope of the study. As a result of these efforts, the following questions emerged as the most pressing:

- What are the needs of PWAs/PWARCs for supportive services?
- What specific services are available to meet those needs?
- How have these services been staffed?
- Are the available services adequate to meet those needs?
- What is the role of volunteers in the provision of services?
- How have counties organized their service responses to the needs of PWAs/PWARCs?

- What are the barriers to supportive services? Do these barriers differ according to ethnicity, gender and culture?

The methods used to answer these questions are described in the following section.

A critical element of our approach to this analysis was the assumption that the least restrictive environment is the most desirable treatment setting for the person with AIDS or ARC. For that reason, this study focuses on the community-based and community-oriented service sector. Although public agencies play an important role in providing necessary supportive services to PWAs/PWARCs, their major contribution is through programs with a community rather than an institutional orientation. While services provided in institutions (skilled nursing and intermediate care facilities) are included in the URSA Institute needs assessment, they are presented as integral components in an array of service arrangements capable of meeting the needs of PWAs/PWARCs. Our assumption, based on the experience in other areas (gerontology, mental health, child welfare) is that populations with functional impairments are best served when they have the greatest possible independence.

## METHODS

This needs assessment study has involved the integration of several different methods of measuring needs. The first step, before any measurement of service need was undertaken, was to define the universe of needs of PWAs/PWARCs. A critical element of URSA Institute's approach to this project was the assumption that needs exist outside the array of services currently available. It was our belief that a needs assessment which relies exclusively on provider perspectives of needs presents only a partial picture. Consequently, the study team attempted to define needs empirically before conducting any analysis of the service response. This was accomplished through a review of the literature, and examination of needs assessment findings and methods in similar service areas, particularly gerontology, and interviews with persons with AIDS/ARC in the San Francisco area. The results of that process were incorporated into the analysis of PWAs/PWARCs service needs described in Chapter Two of this report.

As part of the process of defining the supportive service needs of PWAs/PWARCs, the URSA Institute invited knowledgeable individuals from around the state to sit on an Advisory Committee. The Committee was selected for its experience in providing direct

services to PWAs/PWARCs. It included social workers, hospital discharge planners, directors of community-based agencies and individuals who have been diagnosed with AIDS. Members of the Committee are listed in Appendix A. The Committee met twice. The first meeting was to react to the first draft of the needs model and to assist the study team in refining the field data collection methods. The Committee met again to review and comment on the results of the data collection activities. Their assistance in assuring that the study addressed the informational needs of those involved in the daily effort of serving persons with AIDS or ARC was invaluable. The study team learned much from them.

Once an adequate model of the supportive service needs of PWAs/PWARCs was developed, the study team implemented a three-part data collection strategy. The first part of the strategy was a series of site visits to six counties around the state. The site visits were intended to provide a comprehensive examination of service delivery to PWAs/PWARCs in a local area. The sites were selected in consultation with the Office of AIDS to represent a broad range of community experience in responding to the epidemic. Los Angeles and San Francisco Counties were selected because they have the most experience in serving AIDS/ARC clients and because the evolution of service systems in these two major population centers has been quite different. The second set of sites, Santa Clara and Riverside Counties, was selected to represent large population centers which have begun to experience a large increase in the incidence of AIDS/ARC within the past two years. These sites are self-contained areas which are also sufficiently close to the major population centers of Los Angeles and San Francisco to share some services with them (primarily acute health care). The last two sites, Fresno and Sacramento Counties, were chosen to represent smaller metropolitan areas where the incidence of the disease has grown dramatically within the past year and which are not within convenient distance of other major population centers.

At each of these sites, the URSA Institute study team conducted extensive interviews with as many providers of supportive services to PWAs/PWARCs as could be located. The list of organizations interviewed in each site can be found in Appendix B. While the provider perspective is not the only point of view included in the analysis, it is an important one. Our identification of providers began with the AIDS Community Education contractors in each site. In most counties around the state, those organizations providing educational interventions also provide social and supportive services to PWAs/PWARCs. Using a "snowball sample" or chain referral method, the study team then

asked each provider to identify others who were engaged in serving people with AIDS/ARC. In the larger sites (Los Angeles and San Francisco), as many as a dozen telephone contacts were required before a comprehensive picture of the "AIDS service network" emerged. (In Los Angeles County, we decided not to include Long Beach as part of the analysis. The Long Beach AIDS service network existed almost entirely outside the central Los Angeles system.) In Fresno and Riverside counties, no more than three or four contacts were necessary to complete the picture of the AIDS service network. In each site, the study team believed its picture of the AIDS service network to be complete when our question "Who else in this community works with people with AID/ARC?" elicited no new organizations.

After identifying the organizations involved in supportive services, we scheduled interviews with each of them. The interviews lasted an average of 90 minutes, with a range of 30 minutes to two hours. The study team attempted to meet with all the staff in organizations whose entire client base was PWAs/PWARCs. In broader organizations, such as Visiting Nurse Associations or County Departments of Social Services, we interviewed those staff directly responsible for serving people with AIDS/ARC. In the smaller sites we were able to complete the interviews in two-three days. The larger sites required approximately ten days each to complete the interview process. There was no formal questionnaire used for these interviews. Rather the study team relied on a list of interview points which provided a loose framework in which to pursue needs data. The interview points were:

- the characteristics of the client population
- the specific services offered by the organization
- the use rates of the available services
- staff size and qualifications
- volunteer use
- agency budget
- barriers to service use
- needs for which there were no services



- needs for which the supply of services was inadequate
- the provider's perspective on the organization of services in the community
- the ability of the community to deal effectively with the expected growth in the AIDS/ARC caseload.

From these interviews came a detailed understanding of the AIDS service network in each of the six sites visited.

The second element of the data collection strategy was group interviews with PWAs/PWARCs. Although service providers can describe much of what constitutes a local AIDS service network, our assumption was that a full understanding of service needs can come only from those who experience those needs. These group interviews were organized as focus groups, but were not conducted as formal focus groups in that the selection procedures were not standardized and in some cases the participants were acquainted with each other. In each site, a local AIDS service provider contacted a selection of their clients on our behalf and asked them if they would be willing to participate in a discussion of their supportive service needs and experiences in getting needed assistance. The only requirement was that the participants have been diagnosed with AIDS or ARC. In Los Angeles, San Jose, Sacramento and San Francisco, we conducted multiple groups. In the largest cities, we held special groups for minority and women PWAs/PWARCs. In Sacramento, a special group was held for caregivers. Fresno and Palm Springs (Riverside County) yielded one group each. A total of 42 PWAs/PWARCs were interviewed around the state.

The age range represented in the group interviews was 24-60 years, with an average of 35.2. Males comprised 87.8% of the 42 participants and females accounted for 12.2%. The average number of years of school completed was 13.3. Almost three-quarters (70.7%) of the participants had been diagnosed with AIDS while the remaining 29.3 had ARC. Three-quarters (75.6%) of the participants were white, 14.6% Black, 4.9% Latino, 2.4% Asian and 2.4% from other ethnic groups. MediCal was the most common form of health insurance coverage, with 37.5% of the participants indicating that MediCal paid for their health care. This was followed by private insurance (25.0%). Fully 37.5% indicated that they had no insurance. The geographic distribution of the participants was: 29.4% were interviewed in San Francisco, 26.8% in Los Angeles, 19.5% in Sacramento, 17.1% in San Jose, 4.9% in Palm Springs and 2.4% in Fresno.

Most of the interviews were conducted by a single staff member. For several of the sessions, two members of the study team were present. Each session was audio-taped. After introducing the study, each group began by asking the participants to complete a brief questionnaire (see Appendix C). The intended purposes of the instrument were to collect basic descriptive data about the participants and to stimulate their thinking about the issues to be addressed in the interviews. Once the questionnaires had been completed, the facilitator asked a series of open-ended questions dealing with lifestyle changes and service needs. The data collected from these questions is incorporated in Chapters Three and Four of this report. The sessions averaged 90 minutes in length. At the completion of the interviews, each participant was paid \$20.

The third element of the data collection strategy was a mail survey of a sample of the counties not included in the site visits. This was an important activity in that it permitted us to verify the data collected from the site visits and to learn about supportive services in California's most rural counties. Using the service information obtained from the site visits, the study team constructed a survey instrument designed to elicit the perceptions of supportive service providers about the service needs of PWAs/PWARCs within their counties and the ability of local human service systems to respond to those needs. A stratified sample of 20 counties was selected. The counties were stratified by total population (under 100,000, between 100,000 and 500,000 and over 500,000) and by cumulative prevalence (total number of AIDS cases ever diagnosed per 100,000 population). The selected counties and the survey instrument are included in Appendix D.

Once the sample was drawn, URSA Institute staff began the process of identifying who in each county was most knowledgeable about AIDS service issues. We began by contacting the AIDS Community Education Contractor in each sample county for information about the local service network. In each county, we identified responsible officials in county Departments of Health and Social Services. We also identified physicians in private practice and private human service agencies familiar with PWAs/PWARCs or most likely to serve that target group. Using this process, surveys were sent to 96 specific individuals in the 20 county sample. A total of 47 responses were received from 19 counties, producing an individual response rate of 49% and a county response rate of 95%.

## LIMITATIONS OF THE STUDY

The methods used for this study have generated a rich body of information unlike that collected by any previous statewide research effort. The information is presented and analyzed in the body of this report. However, the URSA Institute recognizes that other methods, such as a survey of PWAs/PWARCs (unavailable due to limitations in budget and time) may have produced a more systematic and quantitative assessment of the supportive service needs of PWAs/PWARCs. Within the constraints of the resources available for this study, we believe that the information collected provides a sufficient base to begin the process of planning for improved services for persons with AIDS or ARC in California.

Within this context, it is important to acknowledge the limitations of the methods used. These are:

- The site visits may not have included all the providers meeting the supportive service needs of PWAs/PWARCs in the six site visit counties. Organizations or individuals not known to the network of providers through which our contacts were made may have been omitted.
- The probability of a selection bias in the choice of participants in the group interviews is high. PWAs/PWARCs who are not receiving services were not available to us, given that participants were recruited through AIDS service agencies. To the extent that PWAs/PWARCs outside of service systems have needs different from those of individuals within those systems, the needs of the "outsiders" have not been addressed. This point is especially germane with respect to minority PWAs/PWARCs and IV drug users who have been diagnosed. Furthermore, the method used (convening a group at a central location) limited the participation of severely ill PWAs/PWARCs who were unable to travel.
- The small number of participants in the group interviews limits the generalizability of the findings even within the population included in the existing service system. Limitations in data availability and budget precluded the use of a probability sample of PWAs/PWARCs.
- For some of the counties included in the mail survey, the answers to questions about the supportive service needs of PWAs/PWARCs are largely speculative.

The counties that have had very limited experience in dealing with the HIV infected population may have based their responses on what they have heard from colleagues or read in professional or popular publications. To the extent that this has occurred, their answers may reflect the experience of others rather than their own firsthand observations.

- The legislative mandate for this study restricts its scope to PWAs/PWARCs. In the course of the data collection, the need for support for those who have been exposed to the HIV virus but are currently asymptomatic was clearly compelling. These "seropositive" individuals require emotional support, help in maintaining their current situations and assistance in keeping strong immune systems. As the proportion of those who have been exposed to the virus develop AIDS/ARC continues to increase, the stress of having a positive HIV test result will take an even greater toll. Their needs must be taken into account in the creation of a comprehensive AIDS service network.

Despite these limitations, the needs data provided in this report offers valuable insight into the the services needed to allow PWAs/PWARCs to live with maximum independence and decency in their communities. The findings also show how a selection of counties have organized public and private human service resources to create an AIDS service network capable of responding to the needs of the infected population. We hope this report will stimulate the further growth of such helping systems.



The following is a list of the names of the persons who have been appointed to the various positions in the various departments of the Government of the State of New York, for the year 1900.

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## **CHAPTER TWO**

### **SUPPORTIVE SERVICES FOR PERSONS WITH AIDS OR ARC**

#### **INTRODUCTION**

Understanding the supportive service needs of persons infected with Human Immunodeficiency Virus requires a special sensitivity to a variety of medical, socioeconomic, cultural and behavioral considerations unique to each individual and, more broadly, to the common characteristics of groups at the greatest behavioral risk of contracting the disease. These individuals enter the formal service system at different stages of their illnesses and with vastly different clinical problems. The capacity to respond to a variety of ameliorative therapies, both proven and experimental, may also determine the course of the illness as well as the type and level of supportive services required by an individual.

Socioeconomic issues such as income and education often circumscribe and frequently limit the therapeutic and lifestyle-related interventions available to the person with HIV infection. Cultural factors also hold significant implications for the sensitivity and overall utility of supportive services, particularly in cultures unaccustomed to reliance on external sources of care. In contrast, HIV infection is also manifesting itself in groups with considerable experience with multiple public agencies leading sometimes to cynicism and a lack of trust toward publicly supported services. These concerns, too, will affect the efficacy of HIV-related interventions.

These dimensions of variation reflect the fact that 1) supportive service needs evolve over the course of an individual's illness and 2) that the circumstances of the illness for each individual hold substantive implications for sensitive and effective service delivery.

## CREATING A FRAMEWORK OF SUPPORTIVE SERVICES

Bringing this framework of supportive services to life requires us to assess the course of a prototypical case of HIV infection from determination of seropositivity, to development and diagnosis of ARC, manifestation of AIDS symptoms, and eventually to increasing debilitation and death. While this illness continuum may not represent the experience of any single infected individual, it does encompass all possible stages of the infection and provides an opportunity to explore service implications across all possible diagnostic circumstances.

As we examine the course of this prototypical case, the need for supportive services can be organized into two general categories of need. These are:

- 1) **Physical Needs:** Here we refer to the basic personal needs of PWAs/PWARCs including assistance with: bathing, dressing, doing laundry, paying bills, mobility, purchasing and taking medications, obtaining legal services, visiting the doctor or hospital, applying for and obtaining disability and related benefits and the most basic daily personal concerns such as: purchasing food and preparing meals, ensuring adequate housing, obtaining an adequate income and related functional needs.
- 2) **Psycho-Social Needs:** Some persons with AIDS or ARC may have difficulty in: maintaining emotional stability, maintaining educational activities, receiving interpersonal support during times of crisis, retaining cognition, and related needs for social and/or psychological support.

In examining the physical/maintenance and psycho-social needs of HIV-infected individuals, it is important to reiterate that not all persons with HIV infection will necessarily develop the various opportunistic illnesses associated with clinical diagnoses of ARC or AIDS. In the next several pages, we describe the needs of seropositive persons, PWAs and PWARCs resulting from their diagnoses followed by a discussion of the implications of these needs on the supportive services system. This understanding of physical and psycho-social needs and appropriate service responses was derived from an extensive series of discussions with AIDS/ARC service providers and with PWAs/PWARCs whose personal experiences and interactions with the support service system were most instructive.



## Physical Needs

The physical or maintenance needs of HIV-infected individuals relate primarily to those whose illness has progressed to the point of opportunistic infection and a diagnosis of ARC or AIDS. For persons with an AIDS or ARC diagnosis, needs can include assistance with basic personal care (bathing, dressing, shopping, etc.) when the illness precludes many activities of daily living due to significant loss of energy or related physical complications. For some, mobility may be impaired resulting in considerable difficulty in carrying out routine activities including travel to medical care. Some persons may need assistance with obtaining and administering medications, others with day-to-day household chores such as cleaning, laundry, bill paying and the like.

The maintenance needs of PWAs/PWARCs will vary, depending upon the presence or absence (and the associated severity) of opportunistic physical illnesses and related dementias. These individuals have lost roommates and housing and some may find income dropping due to continuing absences from work. Routine activities such as obtaining affordable housing and earning an income to support basic needs may be occasionally or chronically impaired resulting in a need for formal and informal supportive care on an intermittent basis.

Further along the HIV infection continuum, PWAs/PWARCs may require intensive medical and hospital treatment, particularly during initial acute episodes and intermittently thereafter. Medications designed to arrest the opportunistic infections may be required by some patients for their entire lives.

Following discharge from the hospital, a person with ARC or AIDS may be able to return home. Some will require skilled or intermediate nursing care which, depending upon the individual's state of health, can be provided at home or in a long-term care facility. For those persons with the most severe cases, discharge from the hospital may be to a hospice to manage the dying process. Health care options for PWAs/PWARCs are circumscribed by the type of health insurance held, if any. Lower rates of reimbursement under MediCal along with restrictions on benefits limit choices, particularly with respect to home- or facility-based long-term care.

The person with AIDS who survives the initial acute episode and is able to live at home may require regular doctor and hospital visits, often as frequently as once per day. Still other persons may need daily assistance with complex medication regimens. At

various times, PWAs may need assistance with daily personal and household duties due to dissipated energy, other physical limitations, and AIDS-related dementias. The level of need for this type of assistance can vary widely for a patient from one week to the next.

During subsequent acute episodes and during the period of progressive debilitation preceding death, the individual may again require intensive medical and hospital care and assistance with all daily household and personal functions. With a diagnosis of ARC or AIDS, maintenance needs often become acute. Following an initial hospitalization, physical limitations can prevent or limit employment with significant implications for income and lifestyle. The wide swings in physical capacity for a PWA/PWARC may effectively preclude work of any sort for discrete periods. Similarly, many PWAs/PWARC need assistance with obtaining and cooking food. This may be partially an income issue and may also be a problem of limited mobility.

Some newly-diagnosed persons with AIDS or ARC may find themselves homeless due to irrational fear on the part of lovers, family, landlords or roommates. As the illness progresses, supported living, intermediate or skilled nursing care or hospice care may also be required. Throughout the course of the illness, appropriate housing and adequate income appear to be the most significant, and intractable, physical needs.

### **Psycho-Social Needs**

Psycho-social needs associated with HIV infection are manifested throughout the illness continuum from the point at which individuals initially contemplate HIV antibody testing to the extended emotional impact of living with a diagnosis of seropositivity, ARC or AIDS. For the past two years, California residents have had available to them free and anonymous testing for the presence of the HIV antibody in their blood. Prior to obtaining the individual's informed consent for the test, testing sites frequently provide some level of education and counseling which describe the purpose of the test, its limitations and the implications (physical and psychological) of a positive or a negative result.

Discussions with seropositive individuals and various service providers indicate that, for an undetermined proportion of seropositives, some level of psychological/emotional trauma results. For some, acceptance of a positive test result appears to occur without obvious difficulty. For many others, however, the positive outcome produces immediate

stress reactions which can often persist over many months, even years. Manifestations vary from a mild but continuing elevation of emotional stress to chronic fear and debilitating anxiety. While testing sites provide some level of counseling to seropositives, the evidence suggests that, for a significant subset of this group, emotional support and educational needs may persist for a considerable period of time following the test.

PWARCs may perceive an ARC diagnosis as "the beginning of the end" despite the fact that a portion of ARC cases diagnosed to date have not developed into clinical AIDS. The immune deficiency associated with ARC can produce a panoply of clinical and psychological manifestations, some of which are self-limiting, others chronic.

Many factors appear to affect the psycho-social needs of the PWARC, including: the extent of the immune deficiency, the specific illnesses manifested, the underlying health status of the individual, lifestyle factors associated with emotional wellness (levels of stress and coping techniques), alcohol and other drug consumption behaviors, and the availability of personal support networks.

Psycho-social needs can be significant for PWARCs because of the "grey zone" in which they find themselves between normal health and an AIDS diagnosis. Stress reactions to the diagnosis can occur on an intermittent or chronic basis and can vary from very mild anxiety to severe depression. Individuals with ARC are sometimes able to continue full employment but many incur illness-related absences which could require confiding their condition to supervisors and possibly to co-workers. Likewise, confronting family, friends and lovers may result in considerable anxiety and, in some cases, loss of informal sources of emotional support.

Dementia or other central nervous system (CNS) disorders are sometimes associated with an ARC diagnosis. In its most advanced stages, the dementia can cause significant disturbance of personality and cognition in turn resulting in problems with nearly all daily living needs.

The psycho-social needs of a person diagnosed with AIDS are often as compelling as are the needs for medical and hospital care. During the period immediately following the diagnosis of AIDS, an individual may be faced with overcoming a serious opportunistic illness. The emotional devastation of a confirmed diagnosis often "turns the world upside down." This may be the most critical period of emotional need for the person with AIDS. Fear, uncertainty, anger and other emotions can often run rampant. Dealing with lovers,

family, friends, business associates, roommates and others can be particularly traumatic and can complicate the PWA's ability to return to some level of emotional normalcy. The need for support, counseling and, for some, regular psychological care following diagnosis emerges at this point.

In the earliest days of the AIDS epidemic, unusual or bizarre behaviors were noted in some infected individuals at the end stages of their illnesses. More recent evidence indicates an earlier emergence of dementia and CNS disorders in some cases. When this occurs, the individual may experience a wide array of affective disorders and difficulty with all aspects of day-to-day functioning.

Ongoing emotional support is required by many PWAs/PWARCs during plateaus and during bouts of acute illness. For some, the certainty of death may have a liberating effect. For most, the likelihood of a vastly shortened life, loss of independence and attractiveness and related complications of the illness present awesome emotional hurdles. During the period immediately preceding death, PWAs/PWARCs may need spiritual as well as general emotional support. Assistance with preparation for dying may also be needed.

### **Special Considerations**

While the physical and psycho-social needs for supportive services described above are intended to reflect the situation of all persons with HIV infection, an examination of the circumstances of particular subpopulations illuminate important nuances in the needs for sensitive support. Persons with underlying substance abuse behaviors may need to address two collateral problems simultaneously, and this group often experiences increased levels of HIV-related debilitation as a complication of the substance abuse. Sources of informal and formal emotional support may be less available to this population due to social isolation, lack of financial resources, social stigma and ostracism. Persons with HIV infection and a significant substance abuse problem may find it difficult to locate permanent housing or temporary shelter--adding immeasurably to malnutrition and related problems.

Also, integrated counseling which addresses the substance abuse problem as well as the psychological implications of HIV infection (particularly with a diagnosis of AIDS or ARC) may represent a crucial but difficult to meet need. Fragmented services for the IV

drug user could seriously compromise the overall effectiveness of both physical and psycho-social support services.

Persons of color who are also HIV-infected require culturally sensitive supportive services largely unavailable currently from the existing mainstream of white, gay-identified sources of care. AIDS-related fear of discrimination may result in a loss of housing and informal support. Problems with securing and maintaining employment may be complicated. Income, traditionally lower in minority groups, may drop to levels which cannot meet basic daily living needs. Homophobia and fear of contagion can produce chronic or short-term psychological and emotional distress. In some cases, existing immune-building interventions (improved diet, regular exercise, control of stress) may not be accessible to people of color. Collateral problems of alcohol or other substance abuse in this population will not only exacerbate the course and severity of the HIV-related illnesses, but may also preclude eligibility for some residential-based supportive services.

People of color, when diagnosed with ARC or AIDS, may find themselves without the formal support and service network others may have access to. Many persons in minority groups (mostly Latinos, Asians and Blacks) have had little exposure to AIDS education. The dual emotional traumas of a terminal illness still conceptualized as a "white, gay disease" can be especially problematic. Sources of hospital and medical care may be severely limited because of cultural differences, lack of knowledge concerning where to obtain services, low income, distrust of public agencies, and absence of adequate health insurance. For many people of color, the overcrowded system of public medical and hospital care may be their only option.

Although women currently comprise a small percentage of the HIV-infected population in California, their proportion of total ARC and AIDS cases continue to rise bringing with it a special set of supportive service needs. For women, psychological/emotional problems of HIV infection may be exacerbated by feelings of aloneness and alienation, fear of confronting a spouse or sex partner (the possible source of the infection), and special concerns about future child-bearing as well as current child-rearing. These circumstances demonstrate the possibility of increased emotional distress because informational materials and counseling may not be adequately targeted to HIV-infected women. The result can be heightened feelings of fear and isolation.

In many cases, HIV-infected women have sole responsibility for parenting. Increased anxiety often results from concerns about the current and future health of their

children, ways to effectively talk with children about their illnesses, how to provide care for their children during periods of severe HIV-related debilitation, hospitalization and after their deaths, as well as associated concerns about maintaining their families in the face of terminal illness.

At present, children constitute a tiny fraction of California's AIDS/ARC population, although their numbers are expected to grow. The supportive service needs of children who are seropositive or have AIDS/ARC depend, to a large extent, on their age, family background, health and functional status. Infants with AIDS may live their entire lives within the confines of a hospital, while school-age children with AIDS/ARC may have a lifestyle approximating that of a non-infected youngster yet requiring home-based sources of support on a regular or intermittent basis. For children with AIDS/ARC and their families, key support services include foster care, adoption and nurturance, particularly if the mother herself is ill. Child care, pre- and after-school care and education on sexuality and drug use are supports likely to be required by older children with AIDS/ARC and their families. For all, emotional support to assist with the psychological burden of AIDS/ARC will be needed.

One group frequently overlooked in the consideration of HIV-related support service needs are the significant others of HIV-infected individuals. The emotional toll of an ARC or AIDS diagnosis can be as traumatic for lovers/spouses, other family members and close friends as it is for the infected person. Concerns about the current and future health of intimate significant others can produce a lasting sense of vulnerability and anxiety. Fear of reaction to knowledge of the HIV infection by neighbors, friends, employers and others can also lead to isolation and social withdrawal. When a significant other participates in the care of a person with ARC or AIDS, he/she frequently assumes the principal caregiver role, oftentimes in addition to full-time employment. This often leads to physical and emotional exhaustion, feelings of frustration, and, on occasion, increased reliance on alcohol or drugs to help them cope with increased stress in their lives.



## **IMPLICATIONS FOR SUPPORTIVE SERVICES**

The problems, issues and concerns raised in the previous pages help lead us to a better understanding of the supportive services required by persons with HIV infection. In the remainder of this chapter, we present an analysis of supportive services which address the needs identified above. The approach taken to understanding the service implications of AIDS/ARC-related needs is based upon the notions that 1) services should be directed towards maximizing physical, mental and emotional functioning, and 2) that services delivered throughout the course of the illness should be provided in the least restrictive physical environment. Because the support service nomenclature is not always employed consistently, Exhibit 1 presents a list of individual supportive services and their definitions.

To most clearly describe these services and the crucial linkages between them, we have developed a service framework which is based upon a diagnostic continuum from determination of seropositivity to death. Clearly, not all persons will travel the full length of this continuum. Some will never progress beyond seropositivity, others not past ARC. Still others may enter the system at the point of AIDS diagnosis. The purpose here is to describe a generic scenario of services which encompasses the broadest set of needs of the most inclusive groups of HIV-infected individuals. Existing supportive service systems and current unmet service needs in California communities are discussed in Chapter Three for physical needs and in Chapter Four for psycho-social needs.

### **Services for Physical Needs**

Meeting the basic physical needs of seropositives, PWAs/PWARCs involves a range of practical and medical services. For seropositives, maintenance of a healthy immune system is essential to prevent a progression to more serious conditions. Adequate nutrition (and nutrition education), regular exercise, management of stress, and elimination of substance abuse are crucial factors for high-level wellness. While often not available from a single source, nutrition assessments and counseling, exercise advice and facilities, substance abuse treatment and support groups, and stress management education are critical service components. Following a diagnosis of AIDS or ARC, medical care becomes a critical service and continues throughout the illness continuum until death. This care



may be provided by physicians, nurses, dentists, and various support professionals in clinics, doctors' offices, hospitals, in other institutional settings, or at home.

Persons with ARC or AIDS may, from time to time, require assistance with mobility. The need for day-to-day transportation (to doctor visits, support groups, shopping, errands) intensifies as disabling conditions are aggravated and become particularly acute for persons with physical debilitation or AIDS-related dementia. PWAs/PWARCs may also require assistance with maintaining a household. Homemaker/chore services provided on a daily or less frequent basis can meet the need to live in a clean, healthy environment. Once again, the level of need for in-home support services can wax and wane but often peaks during the acute illness and chronic debilitation phases of AIDS. Likewise, the need for supportive home care may result from ARC- or AIDS-related dementias.

For persons with AIDS or ARC, the possibility of periodic episodes of severe illness, with attendant progressive debilitation, suggests some level of need for several types of services. In the area of housing, PWAs/PWARCs may be subject to subtle housing discrimination. Fear of contagion and ostracism may cause family, roommate and/or lover problems which can result in a loss of housing. Income loss due to interrupted employment may make housing affordability a problem.

Following the ARC or AIDS diagnosis, need for homemaker/chore, transportation and hospital/medical care services will intensify, although absolute levels of need will vary by the stage and severity of an individual's unique experience. For some PWAs and PWARCs, in-home attendant care may be needed to avoid costly and isolating hospital care, particularly if physical or mental debilitation is significant. Assistance with complex prescription drug regimens, particularly those requiring intravenous or intramuscular administration, may also be required, either in the home or in various outpatient settings.

During potentially lengthy periods of illness, board and care housing with attendant or nursing care available on site is indicated. In the end stages of the illness when chronic debilitation occurs, housing and medical care needs are intertwined and hospice care can become a major need. Post-acute institutional care provided in intermediate care facilities (ICFs) or skilled nursing facilities (SNFs) is required by some PWAs/PWARCs as a transition from hospital to home following acute episodes and possibly during the last stages of the illness when home or hospice care is no longer viable. For persons outside the mainstream service system (IV users, some people of color, persons with low incomes,

some women with dependent children), emergency shelter may represent the difference between survival with dignity and living on the streets.

Many persons with ARC or AIDS have difficulty in maintaining regular employment. This suggests two sets of services. The first is assistance in renegotiating current employment or securing flexible, part-time work. In addition to contributing towards improved income, many PWAs/PWARCs find employment a major means of retaining personal responsibility for their lives and of remaining connected to the outside world. Second, problems in maintaining employment indicate a need for direct cash assistance for basic living needs (rent, food), particularly among those persons ineligible for disability payments. As the illness progresses, employment becomes less consistent (or totally impossible) and, in many cases, income needs rise. It is at this point that the majority of emergency cash assistance requests are made. These income problems can lead to loss of housing, inadequate nutrition and related difficulties.

Adequate food intake is crucial for maintenance of optimum health for persons with AIDS or ARC. Loss of income and chronic debilitation can impede the ability to do (or interest in) food shopping, preparation and consumption. The service solutions include food banks, free or low-cost food, grocery vouchers, food stamps, home-delivered meals and direct cash assistance to provide for at least a maintenance level of food intake.

With the surge of organizations, programs, services and benefits available to persons with ARC and AIDS who may be physically and emotionally limited, client advocacy and case management become important service needs. The degree of need for this service increases when a diagnosis of ARC or AIDS is made, particularly during periods of acute episodes and progressive debilitation. Persons with AIDS or ARC often face needs which require legal intervention. Because income may become problematic, legal assistance and focused advocacy services can be important sources of support.

### **Services for Psycho-Social Needs**

Services designed to meet the emotional needs of PWAs, PWARCs, seropositives and their loved ones are, for the most part, required along the entire illness continuum. The determination of seropositivity can cause significant distress. Emotional support and understanding are critical service elements to limit the risk of more serious illness. Education and information can go a long way in providing reassurance and in guiding the

individual towards a healthy lifestyle and a more complete understanding of their current health status. For seropositive persons with ongoing substance abuse problems, drug treatment, counseling and support are crucial service needs.

An individual with an ARC or AIDS diagnosis likewise requires emotional support, though likely at a more intensive level than that provided to seropositives. ARC/AIDS diagnoses can produce significant emotional reactions and PWAs/PWARCs often need regular peer and/or professional support. Effective education and support can also help to reduce fear, anxiety and depression. For a person with AIDS or ARC and a substance abuse problem, sensitive treatment and counseling linked with ongoing AIDS or ARC support services must be made available.

Following the ARC or AIDS diagnosis, the need for adult day health and respite care can emerge. These services help to meet the less intensive medical needs of the PWA and prevent hospitalization and to provide essential "time off" for family members, lovers and friends who provide the majority of non-medical care to persons with AIDS or ARC. Emotional support services are particularly needed to deal with issues of death and dying, loss, and possible social isolation. In later stages of the illness, various forms of dementia may require intensive professional care and possibly special shelter or hospitalization.

Exhibit 2 presents a schematic representation of the service need model described in the previous pages.

## EXHIBIT 1

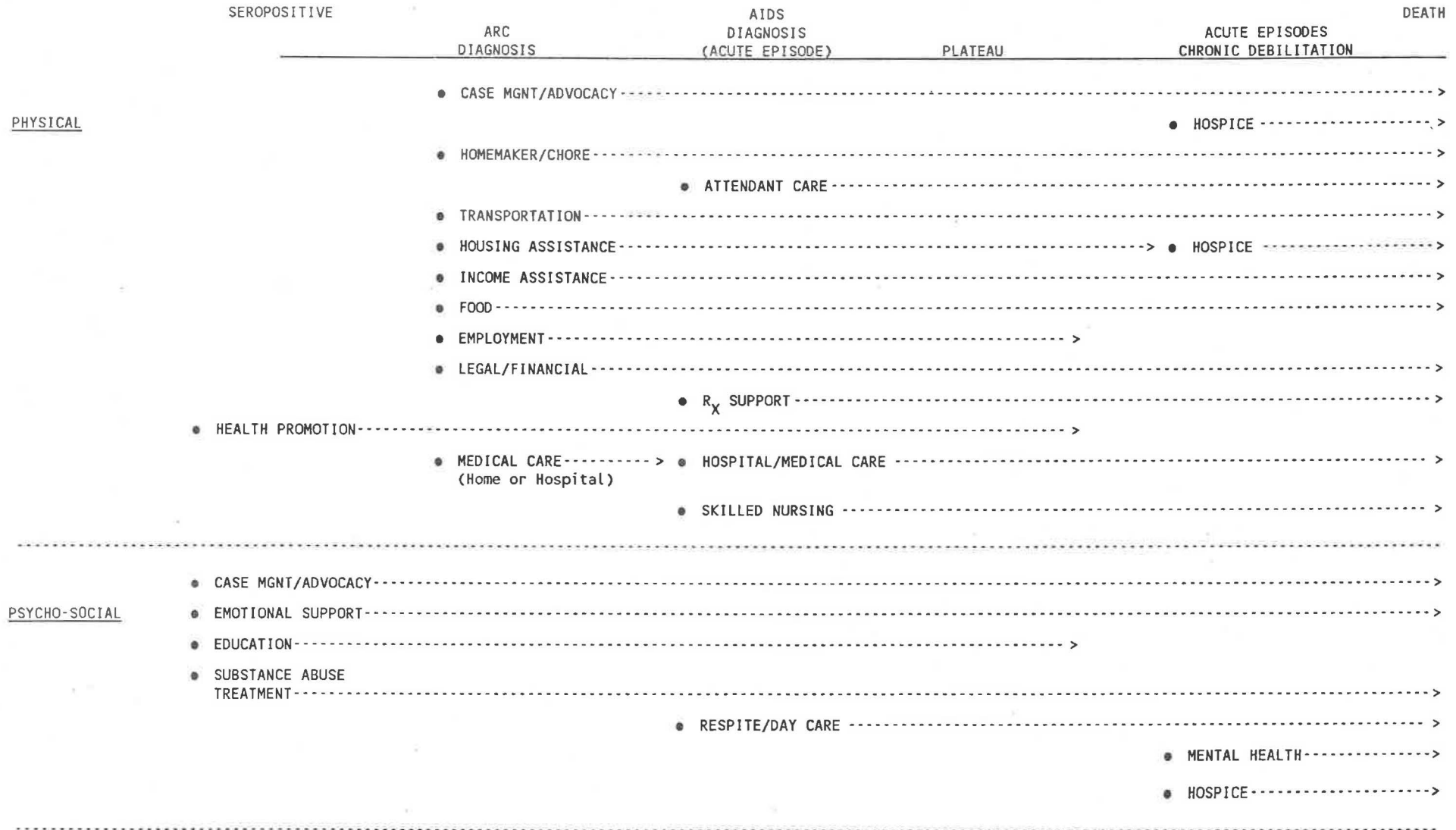
### DEFINITIONS OF SUPPORTIVE SERVICES

ADULT DAY (HEALTH) CARE:	Full- or part-day care, supervised by nursing staff in a facility outside the home. Assistance is also provided with meals, personal care and medication. This service also involves social interaction.
ATTENDANT CARE:	Personal care services (bathing, dressing, cooking, feeding) provided in the home or in a group living setting.
BOARD AND CARE HOUSING:	A group living setting for ambulatory individuals with needs for some level of household support and personal care.
CASE MANAGEMENT/ADVOCACY:	A one-to-one service which ensures that clients receive needed services at the appropriate time in a manner which is acceptable, affordable and of high quality. Case management assists the client in identifying benefits and services, establishing eligibility and resolving disputes. Ongoing client assessments and case planning which integrates health care and supportive services throughout the illness continuum are key elements of effective case management.
CASH ASSISTANCE:	Direct cash payments for basic living needs such as food, housing, medication, clothing and transportation.
CHILDREN'S DAY CARE:	Full- or part-day supervised care for children. Activities are directed toward basic learning and socializing.
CHILDREN'S FOSTER CARE:	Short-term or permanent placement of a child in a family setting away from natural parents.
EMOTIONAL SUPPORT:	May include individual counselling and support groups for infected individuals and their families, friends and lovers.
EMPLOYMENT ASSISTANCE:	Help with identifying appropriate employment opportunities and securing work.
EXTENDED CARE NURSING:	Nursing and personal care provided in skilled nursing or intermediate care facilities to individuals with some degree of physical or mental debilitation. Patient stays in these facilities may vary from a few days to many months.

HOME HEALTH CARE:	Assistance with medication, dressing, physical therapy, physical psycho-social and diagnostic assessments provided in the home or in group living settings.
HOSPICE:	A program of palliative care providing for the physical, psycho-social and spiritual needs of clients and their families. A multidisciplinary team provides support to allow the client to live as fully as possible with emphasis on pain and symptom control on a "round-the-clock" basis. Comprehensive hospice care can be provided at home or on an inpatient basis.
HOUSING ASSISTANCE:	Help with locating affordable housing in the community. Mediation of housing-related disputes.
HOUSING-SUPPORTED:	Rent-subsidized housing.
IN-HOME SUPPORT SERVICES:	Assistance with shopping, cooking, cleaning and related household functions provided in the home.
INFORMATION AND REFERRAL:	Telephone-accessible source of service information and informal support.
LEGAL SERVICES:	Attorney's services, particularly the estate-related services including durable power of attorney, medical durable power of attorney, wills and related legal matters.
PSYCHOLOGICAL COUNSELING:	Clinical psychological services which may address problems of depression, anxiety, fear, dementia and other concerns.
RESPIRE CARE:	Temporary attendant or in-home care provided on an occasional basis to allow providers of informal support (family, lover, friend) time for recuperation and rest. Respite care may also be provided by short-term placement of the client in an inpatient setting such as a skilled nursing facility.
SUBSTANCE ABUSE TREATMENT:	Services (clinical and support) to assist substance abusers in eliminating their habit.
TRANSPORTATION:	Daily or emergency assistance to help with doctor visits, shopping, benefits/service appointments. Also includes ambulance services for transferring patients from one level of care to another.

## EXHIBIT 2

### SCHEMATIC MODEL OF SUPPORTIVE SERVICES FOR PERSONS WITH AIDS OR ARC







## CHAPTER THREE

### PHYSICAL SUPPORTIVE SERVICE NEEDS

#### INTRODUCTION

The physical needs of seropositive persons, persons with ARC and persons with AIDS vary according to the unique circumstances of each affected individual and often fluctuate over the course of the illness. Consistently across the state, PWAs/PWARCs indicated that the initial diagnosis of ARC or AIDS is devastating and "turns the world upside down." For many, adjusting psychologically and practically to the diagnosis requires an array of formal and informal supports which, in some instances, persist throughout the course of the illness and in others occur on a more intermittent basis. Our survey of health and social service providers in 20 California counties, our interviews with AIDS service providers and other agencies in six additional counties and our group interviews with PWAs/PWARCs provide a broad-based understanding of the range of needs which accompany an AIDS or ARC diagnosis (and, to a lesser extent, the determination of seropositivity) as well as the formal and informal sources of support required to address those needs. In the pages which follow, we discuss these supportive service needs. Using the service need paradigm outlined in Chapter Two, we first discuss the range of physical/maintenance needs experienced by PWAs, PWARCs, and seropositives. Chapter Four presents a consideration of the psycho-social needs of these groups along with a discussion of the impact of the illness on the significant others of those affected. (Appendix E presents the combined data from the 20-county survey.)

In our discussions across the state, we learned not only of the tremendous personal impact of an ARC or AIDS diagnosis, but also of the effort required to assemble formal and informal supports to meet the many needs of diagnosed individuals. In many areas, PWAs/PWARCs spend considerable amounts of time identifying and locating support services, qualifying for benefits and receiving the types of support needed to maintain health, functionality and independence. While the time commitment associated with these tasks is most significant immediately following the ARC or AIDS diagnosis, for many individuals the process of obtaining services continues throughout the course of their illnesses as new (and often unexpected) needs emerge. Particularly problematic are the

experiences of debilitated or demented individuals, many of whom rely on agency staff, volunteers, significant others or friends to arrange services to meet their ever-changing needs. It is important to recognize that the needs of PWAs/PWARCs described in these pages are reflective of many of the needs experienced by other disabled or otherwise vulnerable populations. Our consideration of personal needs and service responses are drawn from the rich experience of these other populations including the elderly and the developmentally disabled.

In larger urban areas with the largest AIDS/ARC caseloads, the multiplicity of organizations providing services or benefits to PWAs/PWARCs, each with its own set of eligibility criteria and documentation requirements, creates a complicated, bureaucratic and oftentimes fragmented maze between the client and needed services. In smaller suburban and rural areas, fragmentation is a secondary problem to the virtual absence of many needed services. This trade-off has not been lost on PWAs/PWARCs as they reconsider their residential options and begin to assemble a support service "package" to address their needs.

## SERVICE NEEDS

### Housing

For many persons with AIDS or ARC, housing represents a crucial supportive service need. Following diagnosis, sizable numbers of PWAs and PWARCs experience a change in their housing situation, both voluntarily and involuntarily. Some individuals, shortly following their diagnoses, or at some later point in their illnesses, elect to change their living situations. Reasons for such a change include: reducing housing costs to accommodate significantly reduced income resulting from loss of employment and reliance on government income programs such as Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI) or county General Assistance (GA); relocating to areas more proximate to public transportation, medical care or support service facilities; moving closer to family members, friends or other sources of informal support; or changing residence to accommodate new mobility limitations (e.g., to eliminate stairs in the home).

PWAs/PWARCs in less fortunate circumstances may experience involuntary changes in their housing situations as a result of eviction for non-payment of rent or due to negative reactions to the diagnosis on the part of roommates, lovers, family members or

landlords necessitating an urgent relocation. Changes in health or functional status may also require a change of residence to living arrangements with increased levels of professional or practical support.

In each of these cases, housing becomes a crucial (and sometimes emergency) need for the person with AIDS or ARC. Understanding the housing needs of these individuals involves a consideration of two issues: the need for unsupported (i.e., non-supervised) housing in the open market, and the need for specific types of supported, subsidized or supervised housing to meet special needs.

Approximately two-thirds (65.2%) of respondents from the 20-county survey indicated that persons with AIDS or ARC in their counties were very likely to require affordable (i.e., market) housing following their diagnosis. An additional 26.1% of respondents indicated that affordable housing was somewhat likely to be a need for these groups. Only 8.7% of respondents suggested that affordable housing would not represent an area of need for PWAs/PWARCs in their counties. Not unexpectedly, the highest level of need was reported in counties with populations over 500,000 where vacancy rates are low and housing costs tend to be highest (88.9% indicated housing as a very likely need). This was followed by medium-sized counties (population 100,000 to 500,000) where 67.9% of respondents viewed affordable housing for PWAs/PWARCs as a likely need. In smaller counties (under 100,000 population) where housing costs are generally lowest, 33.3% of respondents indicated housing as a likely need.

Assessing the current capacity of the public or private sectors to meet anticipated housing needs, only 2.2% of all respondents felt that housing resources were currently adequate. A total of 28.9% indicated that some new resources would be needed and 62.2% indicated that many new resources would be required to adequately address the housing needs of persons with AIDS or ARC. In both the smallest and largest counties in our sample, no respondent indicated that the housing needs of PWAs/PWARCs could be met with current resources. In medium-sized counties, fully 96.4% of respondents indicated the need for additional resources to meet expected housing needs.

Discussions with staff of AIDS agencies and other social service and medical care providers in our six intensive sites confirmed the magnitude of the AIDS/ARC housing problem and provided greater detail on the specific types of housing needed. Service agency staff in San Francisco and Los Angeles where both AIDS caseloads and housing costs are highest reported that affordable, market rate housing is nearly impossible to

locate for PWAs/PWARCs, particularly those on SSI or GA. In San Francisco where the monthly GA benefit amounts to \$303, PWAs often must share small inner-city rooms in single room occupancy (SRO) hotels with no cooking facilities and shared baths. This consumes the largest share of their monthly GA benefit. Even for PWAs and PWARCs with slightly larger benefits under the SSI and SSDI programs, market housing remains very difficult to locate. In rural and suburban counties such as Fresno, Sacramento, Riverside and Santa Clara, where a current rental housing surplus exists, market housing on a private and shared basis is somewhat less problematic.

In all areas of the state, specialized types of housing to meet the special support needs of segments of the PWA/PWARC population are either non-existent or are full to capacity. Board and care (B+C) housing is the most striking example. Board and care facilities meet basic housing needs and provide elemental practical assistance and supervision to ambulatory clients with minimal support needs. In rural and suburban counties, supervised board and care facilities for the elderly and developmentally disabled are at full occupancy or otherwise unavailable to persons with AIDS or ARC. In San Francisco and Los Angeles, the handful of B+C facilities operated by AIDS social service and other charitable agencies are operating at full capacity with waiting times often in excess of three to six months.

The situation for group housing is comparable to that for board and care. In the large, urban counties, group residences operated by the San Francisco Shanti Project and other agencies are at full capacity with long waiting lists. In rural/suburban areas, no such facilities currently exist and problems associated with liability, operating responsibility and total project cost are likely to retard development efforts. Agencies in Sacramento and Santa Clara counties, whose caseloads have increased dramatically in the past 18 to 24 months, are currently developing plans for AIDS/ARC group housing but admit that, realistically, the availability of a small number of group housing beds is, at best, 12 to 18 months away. In the smaller counties, other urgent needs, limited agency funding, anticipated local opposition and agency staff shortages have prevented even the consideration of developing group living arrangements for persons with AIDS or ARC.

Partial and fully-subsidized housing was identified by agency staff in all counties as a needed service for very low income, debilitated or demented PWAs/PWARCs. Waiting lists of several years and extremely limited availability of Section 8 housing or housing subsidies make subsidized housing unavailable in all areas. Thus far, charitable

and religious organizations have been unable to address the subsidized housing need which continues to rise as the growing numbers of persons with AIDS or ARC spend down their savings and become dependent on government income subsidies.

According to AIDS agency staff in each of our six intensive sites, the housing problems experienced by PWAs/PWARCs is even more acute for IV drug users, alcoholics, and for women, particularly those with dependent children. When housing services for persons with AIDS exist, agency policies are especially firm with respect to IV drug users (IVDUs). For placement in board and care or group homes, IVDUs must be actively engaged in a substance abuse treatment program. For persons with AIDS or ARC and an untreated drug use problem, housing of any sort is "impossible to locate" according to numerous respondents. In Sacramento, two small community agencies which provide emergency shelter to the homeless and to drug users accept persons with drug use problems on a short-term, emergency basis although the availability of beds is severely limited and cannot meet even current levels of need.

Where specialized housing services for PWAs and PWARCs are available, women are routinely accepted. Women with dependent children, however, present a special challenge to the service system. Currently, no services exist which permit mothers with ARC or AIDS to be placed in residences with their children. Thus, keeping families together where the infected mother is the head of the household becomes especially difficult and painful to the client and to frustrated staff at AIDS service agencies.

One final aspect of the housing situation where current needs remain unmet is for temporary emergency shelter. Persons with AIDS or ARC are, upon occasion, subject to various forms of housing discrimination as well as other crises which can lead to abrupt termination of existing living conditions and a need for emergency shelter. Women with ARC or AIDS have been abused by their mates; roommates and landlords have immediately evicted newly-diagnosed individuals; IV drug users have been put out on the street. Emergency shelter needs have been experienced in all areas of the state and few formal services have developed to meet these urgent needs. Volunteers with spare rooms have stepped in to provide help in some areas and specialized shelters (e.g., those for abused women, homeless) have accepted PWAs and PWARCs but the level of need for emergency shelter, particularly in large urban areas, far exceeds currently available resources.

A San Francisco woman infected with HIV since 1979 and diagnosed with AIDS several years later bore four children, three of whom died prior to their sixth month from

mysterious, debilitating illnesses, later diagnosed as AIDS. Her remaining child, now 6, has ARC. Living in a physically and emotionally abusive relationship, the woman desperately needed to change her (and her daughter's) living situation and "get my life, whatever's left of it, back together." AIDS residences were filled to capacity and the physical abuse required an urgent relocation. A privately-operated battered women's shelter took in the woman, emergency foster care was found for the child and case management by staff of the San Francisco AIDS Foundation helped to arrange for an array of needed supportive services. As AIDS/ARC caseloads increase, more formalized systems of housing and other support will become a critical community need for infected mothers and their dependent, possibly HIV-infected, children.

Our group discussions with persons with AIDS or ARC throughout the state shed light on the human implications of the AIDS housing crisis. In all areas of the state, PWAs and PWARCs strongly favored the creation of group living and board and care facilities. They offered several reasons for their strong support of these housing options. Group or B+C housing would achieve certain economies of scale by allowing pooling of limited in-home supportive services and home health and hospice hours allocated to several clients. Peer support among PWAs/PWARCs would become more available within the B+C or group living residence. On-site chore sharing would ensure adequate upkeep but would not overburden individuals during periods of extreme debilitation. For these, and other reasons, PWA/PWARC group living received considerable attention in nearly all group discussions, attesting to the severity of the housing problem in all areas.

Service providers in several areas raised issues related to group housing for persons with AIDS or ARC. One concern related to the emotional effect on residents from witnessing the inevitable debilitation and death of other residents. Such a burden could easily overwhelm individuals sharing close quarters, causing increased rather than lessened emotional difficulties. Providers also noted that PWAs/PWARCs experience considerable stress associated with their illnesses. Group homes could amplify their stress and lead to conflicts and difficulties which could be both psychologically and physically damaging. Chronic debilitation and fatigue often associated with AIDS or ARC could prevent residents from fulfilling household obligations, placing increased responsibility on other residents. Finally, service providers throughout the state identified the need to integrate AIDS/ARC group housing with the full array of community-based supportive and health care services, particularly because most group residences would be unsupervised.



A number of group discussion participants indicated that assistance in locating affordable housing represented an important unmet need. For some, the long and complicated process of looking for affordable housing was beyond their compromised physical abilities. This created feelings of despair and helplessness and added greatly to the financial and emotional burden of the disease.

Several persons with AIDS or ARC, mostly in the Sacramento, Fresno and Santa Clara areas, indicated that primarily because of financial considerations, they had returned to parents' or siblings' homes to reside permanently. While a number of these situations appear to have worked out well, some participants indicated that lack of other housing options had placed them in intolerable and stressful living situations where they "felt trapped" and "had to walk on eggshells" to avoid serious conflicts with family members. These personal themes were perhaps the most poignant because of the feelings of hopelessness created by the lack of alternative housing options.

### **Practical Help in the Home**

For persons with AIDS or ARC whose living situations are stable, periods of extreme weakness, debilitation and compromised functionality create a need for practical help in the home. Needs for cooking, cleaning, shopping and related household chores necessarily vary by the health of the individual and the availability of informal sources of practical support such as roommates, lovers, neighbors, friends and family. Help in the home ensures that necessities of daily living are accommodated for the individual who cannot perform these functions him/herself. The In-Home Supportive Services (IHSS) program represents the formal service response to this need, while practical support volunteers ("buddies") address this issue on a more informal basis. For bedridden or homebound persons with AIDS or ARC, a clean home environment and freedom from concern about daily necessities can make an important contribution to the overall quality of life.

In-home practical support services were identified by four-fifths (80.4%) of survey respondents in our sample of 20 counties as a very likely need of persons with AIDS or ARC. Another 15.2% indicated that "help with cleaning or cooking at home" represented a somewhat likely need. There was very little variation in the perception of this service need by the size of the respondents' counties. Clearly, the debilitating aspect of the

illness is well understood by health care and social service providers in all 20 counties and reflected one of the three greatest areas of perceived service need.

With respect to existing service capacity to meet in-home support needs, only 13.3% of all respondents indicated that this need currently could be met in their counties. Nearly half (48.9%) of the respondents indicated that some additional resources would be required to respond to this need while one-third (33.3%) reported that many new resources would be needed. The only discernable variation in the perception of current in-home support service capacity by county size dealt with the need for new resources. In small counties, none of the respondents felt that in-home support needs of PWAs/PWARCs could be met with current resources. Nearly one in five (18.5%) respondents from medium-sized counties felt that current service capacities are adequate. For large counties, 11.1% indicated adequate services are currently available. Across the state, health care and social service providers have recognized the severity of the need for in-home help but few expect to be able to meet these anticipated needs without some degree of new resources.

Discussions with AIDS service providers in the study's six intensive sites indicated that the vast majority of in-home practical support is provided on an informal basis by lovers, roommates, family members, friends and practical support volunteers associated with AIDS service agencies. Only a small fraction of the need for in-home support is derived from the state/county IHSS program. As AIDS/ARC caseloads increase, reliance on volunteer and other sources of informal household support will become increasingly problematic. Problems already have been experienced by AIDS service agencies in several areas in matching practical support volunteers with "difficult" (i.e., noncompliant, demented or verbally abusive) clients, often persons with active IV drug use problems. Similarly, the physical and emotional toll on lovers, family members and friends, of providing daily assistance to PWAs/PWARCs can be especially trying. Reliance on these informal supports creates a fragile system of meeting critical living needs of persons with AIDS or ARC which cannot reasonably be expected to meet future service needs.

While voluntary help in the home was seen as critical for maintaining PWAs/PWARCs in their homes, this help is, regardless of the source, often provided by otherwise employed persons whose availability to the client is generally in the evenings or on weekends. This limitation could be filled by paid daily IHSS chore workers, but due to limitations in per-client service allocations and difficulties associated with locating trained workers, IHSS has had limited impact in many areas. According to many AIDS



service agencies, the system of practical, in-home support should function with volunteers supplementing paid IHSS workers in order to lessen the caregiving burden on significant others and volunteers.

On the voluntary, or informal, side, several agencies which provide these in-home services reported a difficulty in recruiting a sufficient number of practical support volunteers. In San Francisco, a shortage of volunteers limits Shanti's practical support caseload and in Sacramento, only 20% of the Sacramento AIDS Foundation's volunteers have signed on for practical support duties.

The IHSS system was reported by many agencies to be a useful, but underfunded program which was incapable of meeting the in-home support needs of many persons with AIDS or ARC. Two principal problems were mentioned in each of our six intensive sites. The first was a matter of the number of IHSS hours authorized per client per week. Many AIDS providers felt that authorized hours were generally inadequate to meet clients' needs. Methods of calculating required duties and their associated time allocations, coupled with fixed monthly benefits limits often precluded adequate levels of care, particularly for the most seriously debilitated clients.

The second issue associated with the IHSS program related to the availability of competent chore workers willing to work with persons with AIDS/ARC. Few IHSS offices offer assistance in locating workers and few county policies allow payment above the federal minimum wage. Without an updated worker registry, clients (or members of their support systems) assume full responsibility for locating a \$3.35/hour chore worker competent and willing to care for a person with AIDS or ARC. Where presumably competent workers are available, many refuse PWA or PWARC clients. In other situations, the low hourly wage must be supplemented by the client or by a voluntary cash assistance program in order to attract competent workers. In Sacramento, for example, the family of a PWA interviewed over 40 prospective IHSS workers over a six-week period before one was hired--one week prior to their son's death. Similar examples are found in other counties, as well.

Service providers in several counties felt that higher allowable hourly wages, increases in authorized hours per client and a central IHSS worker registry could begin to address the rapidly-growing need for in-home support as a means of preventing needless hospitalization and maintaining the physical, social and emotional independence of their PWA and PWARC clients. Others felt that IHSS workers should be provided with at least

basic information or training on caring for a PWA/PWARC. Such information is not currently provided in the six counties we visited for this study.

Our discussions with PWAs and PWARCs around the state supported the notion that in-home support is an essential component of the "package" of supportive services required by most individuals during discrete periods of their illness and for some throughout the entire course of the disease. The most consistent themes concerned the difficulty in locating workers, inadequate levels of authorized hours and complicated and restrictive eligibility criteria. Particularly concerned were PWARCs whose eligibility for IHSS is severely restricted but whose needs for services in the home parallel those of PWAs. Group discussion participants recounted problems associated with their determinations of eligibility for IHSS. If the client has not previously qualified for SSI, the process of determining disability can, and often does, extend over several months. In the interim, a short-term but acute problem with daily household needs can emerge, placing a considerable burden on the debilitated PWA/PWARC, social service agencies, volunteers and significant others.

As is the case with a number of the government-supported benefits and service programs, PWAs and PWARCs seeking to initially qualify for the IHSS program were often met by intractable and unhelpful bureaucracies. A noteworthy exception occurs in Santa Clara County where a staff member in the county social service office personally expedites AIDS/ARC applications, reducing the confusion attendant to the application and eligibility documentation processes and significantly reducing the wait time between application and authorization. This facilitation is done on the basis of personal concern and is not yet a formal policy of the Social Service Department.

## **Hospice**

Closely related to the need for in-home assistance is the need for hospice services, particularly for individuals near the end of their illnesses. In most areas, hospice organizations provide emotional and medical (e.g., nursing) help to the most severely debilitated, bedridden and homebound PWAs and, to a lesser extent, PWARCs. Hospice services are generally provided in the home although some agencies reserve dedicated hospital beds for clients with intermittent or end-stage care needs. In San Francisco, the new Coming Home hospice operates its own inpatient facility.

Our survey of respondents in 20 counties indicated that nearly three-fourths (71.7%) felt that hospice services are a very likely need for persons with AIDS or ARC. Another 21.7% indicated hospice as a somewhat likely need and only 6.5% of respondents felt that hospice services would not be needed by PWAs and PWARCs in their counties.

Respondents in larger counties with higher caseloads were somewhat more likely to indicate hospice as a very important need (88.9%) than were those in medium-sized (67.9%) or smaller (66.7%) counties. Interestingly, respondents in the smaller counties were far more likely to report no need for hospice (22.2%) than did those from medium-sized (3.6%) and larger (0.0%) counties.

A total of 30.4% of all respondents felt that hospice service needs could be met with current resources. Over a third (37.0%) indicated the need for some new resources and 28.3% felt that many new resources would be needed for hospice care. Medium-sized counties were the most confident regarding their current ability to meet hospice needs with 39.3% of respondents reporting adequate existing capacity. Only 11.1% of those from large counties and 22.2% of those from smaller counties felt that current hospice resources were adequate.

Our interviews with health care and AIDS service providers indicated that hospice is a key element of the AIDS service system for two reasons. First, it helps to maintain the maximum independence of PWAs with limited functional capacity. These persons, with severely limited mobility, might otherwise not receive needed support during the latter stages of their illnesses. Second, hospice and associated home nursing care can prevent or delay costly hospital stays. In San Francisco, for example, one PWA remained in the hospital for nearly 11 months until a hospice facility bed became available. In some cases, hospice care, both in-home and facility-based, can serve as a less intensive surrogate service for the institutional care often provided in intermediate care and skilled nursing facilities.

The need for hospice services has been recognized in each of our six intensive sites. San Francisco Home Health and Hospice is a key element of the city's AIDS service network. In Sacramento, a consortium of six hospice providers address the needs of PWAs and PWARCs. In Fresno, the county hospital has assembled a hospice service for PWAs by tying into existing county services (public health nursing), local professional schools (student nurses and social workers) and volunteer organizations.

Most hospice agencies serving persons with AIDS/ARC provide at least minimal services to clients regardless of ability to pay. Where private insurance is held by the client, the carrier is billed. IHSS allocations can also be integrated with donated staff and outside volunteer time to obtain at least partial hospice coverage. For low income persons without IHSS or private health insurance, hospice care is sometimes provided without charge, depending on service availability.

Hospice services address important needs of many persons with AIDS or ARC. Service providers in several areas, however, experienced some concern regarding the applicability of the traditional hospice model for PWAs/PWARCs. The traditional hospice model was developed primarily for elderly individuals whose life expectancy, at a maximum, was six months with a predictable downward trajectory in health and functional status. Persons with ARC or AIDS, however, may experience important changes in their health and functionality over the course of their illnesses. They may live well beyond the six-month period around which hospice service models are based. Hospice services provided in the client's residence assume the availability of an informal caregiver in the home. The absence of such a caregiver, a common situation for some PWAs/PWARCs, limits the effectiveness of the hospice model and may well place a burden on the hospice provider which the organization may not be adequately equipped to meet. Despite these realistic concerns, traditional and adapted hospice services currently address an array of practical, health-oriented and psychological needs of terminal PWAs/PWARCs.

In the group discussions, clients perceived hospice care in much the same way as they did in-home support, as a means of retaining independence and delaying hospitalization. Several participants noted that hospice services help to lessen the caregiving burden on loved ones and volunteers. Many participants felt that they would make use of hospice services in the home and, if available, in a hospice facility to make the last weeks and months of their illnesses as comfortable as possible for themselves and for their families.

#### **Home Health/Medication Assistance**

Persons with ARC or AIDS frequently experience fluctuations in their health status, functionality, mobility and overall energy levels throughout the course of their illnesses. Because of the unpredictable onset and course of various opportunistic infections, the

need for home health care and in-home assistance with the administration of prescription medications and IV drips generally occurs on an intermittent basis. The availability of these home-based services often can prevent or delay hospitalization of the client. Home health care, then, fills a need for persons who do not require the full array of inpatient services but who cannot, because of mobility limitations, avail themselves of traditional medical outpatient services.

Help with medications was reported by over half (54.5%) of the 20-county survey respondents as a very likely need of persons with AIDS or ARC in their counties. An additional 38.6% indicated that the need for this service would be somewhat likely for their AIDS/ARC population. In the largest and the smallest counties in our sample, 77.8% of respondents indicated help with medication as a very likely service need. In medium-sized counties, 38.5% of respondents indicated a high likelihood of need. Overall, 6.8% of all respondents felt that help with medications was not needed, and virtually all of these respondents represented small counties with very low AIDS/ARC caseloads.

Only 15.6% of all respondents felt that current resources could meet the expected need for in-home medication assistance, while 75.5% indicated that some level of new resources would be required to address this area of need. Variation by county size was not substantial with regard to existing service capacity.

In most intensive sites, assistance with medications and home health care is provided by public health nurses and private home health or home nursing agencies, both hospital-based and independent. In the largest counties with the heaviest AIDS/ARC caseloads, problems have centered on the capacity of the public health system to respond adequately to individual needs. Several service providers indicated that skilled nursing assistance with drips, infusions and IV medications is particularly difficult to arrange because of low MediCal reimbursement rates and insufficient allocations of in-home skilled nursing hours.

In smaller, rural counties, barriers to the delivery of medication assistance and home health services include the lack of private insurance or other sources of reimbursement, large geographical areas with widely dispersed AIDS/ARC populations and the unwillingness or reluctance of some public and private nurses to accept AIDS or ARC cases. The solution to the latter problem is clearly one of professional and public education to provide accurate information on appropriate treatments and virus transmissibility, according to a number of AIDS service and education agency staff.

In group discussions, persons with AIDS or ARC with complex drug regimens expressed the need for expanded home health care and assistance with medications as an important means of maintaining independence during difficult periods of their illnesses. They viewed it as a key factor in preventing repeated hospitalizations or complicated (and often debilitating) daily trips to hospital outpatient facilities.

### **Post-Acute Care**

The most consistently identified gap in services for persons with ARC or AIDS is the lack of available post-acute skilled nursing and intermediate care beds. From large urban areas to smaller rural communities, the shortage of skilled nursing facility (SNF) and intermediate care facility (ICF) beds has placed considerable strain on the acute health care system and on the providers of various support services programs, particularly those which are provided in the home.

SNF and ICF facilities provide post-acute nursing and custodial care to individuals recovering from an acute illness and to individuals whose physical or mental health status precludes living at home or in a group living situation but for whom hospital care is not yet appropriate. SNFs provide a higher level of skilled nursing care to patients while ICFs offer more custodial types of care. Together, SNFs and ICFs represent a continuum of post-acute residentially-based care which can fill an important set of physical needs for persons with AIDS or ARC at various stages in their illnesses.

A total of four-fifths (80.4%) of respondents to the 20-county survey felt that skilled nursing care was a very likely need; an additional 13.0% saw it as a somewhat likely need. These perceptions, however, varied dramatically by county size. Fully 100% of large county respondents indicated skilled nursing care as a very likely need, while 82.1% of those from medium-sized counties and only 55.6% from smaller counties had similar perceptions of the level of need.

The pattern was nearly identical when asked about the need for intermediate care. Overall, 91.3% saw this as a very likely or somewhat likely need. However, 100% of large, 64.3% of medium-sized and 55.6% of smaller counties identified intermediate nursing care as a very likely need for persons with AIDS or ARC.

The existing capacity of the SNF/ICF system to respond to expected AIDS/ARC needs was perceived quite differently by counties of different sizes. Overall, 17.4% of all



respondents felt that existing SNF resources could adequately address anticipated AIDS/ARC needs. Smaller counties were most optimistic, with 22.2% indicating confidence in current SNF resources. A total of 21.4% of respondents from medium-sized counties and no respondents from larger counties reported satisfaction with skilled nursing care for their expected AIDS/ARC caseloads. Intermediate care resources were perceived as adequate by only 2.2% of all respondents, all from the smaller counties included in the survey. A total of 78.3% of all respondents indicated that new resources will be needed to adequately provide skilled nursing care to PWAs/PWARCs, while fully 93.4% so indicated for intermediate nursing care.

Skilled and intermediate care facilities throughout the state operate near full census and few will accept persons with AIDS or ARC for several reasons: fear of patient, family and community reaction, the "heavy care" needs of some PWAs/PWARCs, and the low daily reimbursement rate paid for SNF and ICF care by MediCal. AIDS service providers in some areas note that SNF/ICF facilities reportedly will not accept AIDS/ARC clients because state regulations preclude providing SNF/ICF care to individuals with a contagious disease, although AIDS and ARC do not fit current definitions of "contagious." According to AIDS agencies in San Francisco, Sacramento, Fresno and Los Angeles, the lack of available SNF or ICF beds has kept AIDS and ARC patients in the hospital well beyond appropriate discharge times. The result is continued back-up of persons with AIDS or ARC in costly hospital beds, oftentimes needed by other patients in acute situations.

In many areas, hospice, home health, IHSS and practical support volunteer teams are assembled to provide ICF-like care in the home. Assembling these in-home teams is often problematic because the absence of a single element could prevent discharge from hospital to home. The complexity from a case management perspective of arranging for these providers, particularly in smaller, resource-poor communities can be daunting.

The relatively recent emergence of AIDS and ARC in California women has added an important nuance to the SNF/ICF issue. Providers in areas with female AIDS and ARC cases are wrestling with the difficult problem of maintaining the relationship between a woman and her dependent children, especially during periods of acute and post-acute care. With limited case experience to date, no formal post-acute care systems or other housing options have been developed, and volunteers, family members and friends have provided support such as child care, as needed. Several agencies experienced deep

concern about caring for women with dependent children, especially as the number of women with ARC or AIDS rises.

Providing care in the home is often desirable for cost and life quality reasons, as the APLA Home Health and Hospice Demonstration has shown. Yet for some individuals, transitional SNF or ICF care is both medically appropriate and cost-effective and the need for these alternatives, already critical, is expected to expand dramatically as AIDS and ARC caseloads grow.

### **Meals/Groceries**

Maintaining independence and maximizing functionality and mobility are common themes associated with an array of in-home services. Because proper nutrition is key to maintaining weight and improving overall health status, the availability of home-delivered meals and free or low-cost groceries are important components of the support service "package" needed by many PWAs/PWARCs.

Home-delivered meals provide one or two hot meals daily to homebound and bedridden clients who might not otherwise have access to regular daily meals because of debilitation or dementia. Programs such as Meals on Wheels in San Francisco or Meals a la Car in Sacramento originally developed to serve older adults but have responded to the needs of PWAs/PWARCs. Services are provided at low cost and are paid for by the client or by various charitable organizations. AIDS service agency staff in Fresno and Riverside indicated that such a service was not routinely available to their clients with the exception of limited meals programs provided by religious or charitable groups. This gap was considered a potentially serious one, particularly for individuals living alone during periods of severe debilitation.

For PWAs and PWARCs on severely limited incomes, the need for free or low-cost groceries is particularly critical. AIDS food banks in San Francisco and Los Angeles address this need but other areas have not yet developed these resources. In Sacramento and Fresno, for example, community surplus food agencies and religious groups have directed their efforts to persons with AIDS or ARC in their communities. In Riverside and Santa Clara, no formal food bank program exists although voluntary organizations will try to meet emergency needs as they arise. A sizable portion of the emergency cash



assistance provided to PWAs/PWARCs supports the purchase of food and groceries in most counties.

The state's most notable food bank program is the "Bare Necessities" AIDS/ARC supermarket, administered by the AIDS Project Los Angeles. The donated foods allow for considerable variety, including fresh fruits and vegetables. Debilitated PWAs/PWARCs may telephone orders and have them delivered by APLA volunteers. A special rest/social area allows for socialization and volunteers are available to shop for those too weak to do so for themselves. Bare Necessities is unique by virtue of its size, selection of foods and strong volunteer component. Sadly, no other food bank program in the state is able to offer this crucial service at this level to its PWA/PWARC clients.

In focus groups, PWAs and PWARCs acknowledged the importance of home-delivered meals and food banks as a way to stretch their limited incomes. Several concerns emerged, however, with respect to these programs. For home-delivered meals, PWAs and PWARCs in several counties reported that the quality and taste of the meals were poor and did not encourage consumption. Often the food was considered bland and institutional, with little day-to-day variety. This was seen as discouraging adequate caloric intake, so essential to persons trying to maintain adequate body weight. Vitamins and nutritional supplements are not usually included in AIDS/ARC food bank programs, largely because of the high cost of these specialized products.

Food banks were viewed very positively by group interview participants. Concerns arose, though, regarding weekly limits on the amount of food and groceries allocated to each client. Several individuals also reported that fresh fruits and vegetables were often not available and that foods appropriate to low-salt, low-sugar or yeast-free diets often had to be purchased independently of the food bank. While these issues were troublesome for a number of individuals, some PWAs/PWARCs, particularly those with the lowest incomes, found both home-delivered meals and food banks to be among the most important regular components of their support service systems.

### **Transportation**

Many of the support service needs described in the previous pages relate to housing and in-home services. This reflects the periodic (and sometimes chronic) weakness and loss of mobility associated with ARC or AIDS and the strong desire to remain at home

with maximum possible independence on the part of many PWAs/PWARCs. Nevertheless, most persons with AIDS or ARC must travel on a regular basis to doctor and hospital appointments, for appointments with government agencies and social service groups, for recreation and for routine chores and errands. Medically attended transportation is sometimes needed for transporting seriously ill clients from home to hospital and vice versa. The availability of transportation, either routine or medically attended, emerges as an important need for PWAs/PWARCs without access to a private automobile or during periods of significant debilitation, disfigurement or dementia.

Over two-thirds (67.4%) of respondents to our 20-county survey indicated that transportation was a very likely need for persons with ARC or AIDS in their counties. An additional 26.1% felt that transportation was a somewhat likely need and only 6.5% of all respondents indicated no need for this service. Smaller counties were least likely to perceive a transportation need with fully 22.2% of respondents in those counties indicating no service need in this area. Only one respondent in the medium-sized or large counties indicated no need for transportation services. Large counties reported the highest level of transportation need, with 88.9% of all respondents indicating it as a very likely service need.

Overall, only 6.7% of survey respondents felt that existing transportation services could meet anticipated levels of need. Better than half (57.8%) indicated that some new resources would be required and 28.9% felt that many new resources would be required to address the transportation needs of their AIDS/ARC population. Large counties (12.5%) and small counties (11.1%) felt more confident in their existing level of transportation services than did medium-sized counties (3.6%). And between 22.2 and 32.1 percent of respondents in all counties indicated a need for considerably more transportation resources in the near future.

In Los Angeles, APLA operates an extensive, volunteer-based transportation program to medical services, while discounts on public transit and the citywide paratransit system addresses some of the transportation needs of PWAs and PWARCs in San Francisco. Other counties rely on volunteer transportation services, but liability problems have hampered programs in some areas.

Staff from AIDS agencies in suburban and rural counties indicated that the vast majority of transportation assistance is provided by lovers, family members, friends and neighbors. Church and voluntary groups assist in some areas. As with other services,

transportation assistance provided informally by these individuals often is available outside of normal business hours, whereas persons with ARC or AIDS most need them for doctor visits, social service appointments and errands during the business day.

Emergency transportation, generally by ambulance, is available in all counties but some problems were noted with respect to the high cost and limited reimbursement for ambulance services. Concerns also were raised about the attitudes of some attendants toward transporting persons with AIDS or ARC.

Public transit was seen as a viable option only in San Francisco with its Muni and BART systems. Other, more dispersed areas, both rural and urban must rely on organized programs (as in Los Angeles) and family, friends or volunteers (as in Fresno and Sacramento). Even in San Francisco, public transit was not seen as a viable option for debilitated, disfigured or demented individuals or for most PWAs/PWARCs during cold, inclement weather.

Group interview participants repeatedly reinforced the importance of transportation as a routine need. Many PWAs and PWARCs had relinquished their private automobiles because of cost or disability. Absence of transportation greatly increases social isolation and contributes to feelings of dependency. In areas where transportation programs were in place, PWAs/PWARCs indicated that services were often available only for medically-related appointments and that equally important non-medical needs could not be met. Transportation programs generally require a minimum of one to two days prior notice, causing difficulties for some clients with same-day transportation needs. Others in areas not served by formal programs relied on informal sources and many reported a curtailment of their activities to lessen the burden on family members, volunteers and others.

### **Legal Services**

Persons with AIDS or ARC often experience a need for legal services at some point in their illnesses. Individuals may wish to deal with estate issues, such as wills and trusts, or with concerns related to anticipated disabilities, such as living wills, powers of attorney and durable medical powers of attorney. Some persons with ARC or AIDS may require legal assistance to deal with housing- or employment-related discrimination or to appeal rulings on eligibility for government benefits and services. While legal needs exist

for large numbers of PWAs and PWARCs, few low-cost or free services exist currently to meet those needs.

Just under half (46.7%) of the respondents to our 20-county survey indicated that legal services represented a very likely need for PWAs and PWARCs in their counties. Another 40.0% felt that legal services were a somewhat likely need. A total of 13.3% did not consider legal services as a current or an anticipated need for their AIDS/ARC clients. Respondents from larger counties were most likely to see a need for legal services (88.9% very likely, 11.1% somewhat likely). Mid-sized counties were next (39.3% very, 50.0% somewhat likely need). Smaller counties with the lowest AIDS/ARC caseloads were far less inclined to see a need for legal services (25.0% very likely need, 37.7% somewhat likely need, 37.5% no need).

Across all survey respondents, 13.0% felt that current resources were adequate to meet anticipated needs for legal services; 58.7% suggested the need for some new resources; and 19.6% indicated that many new resources would be required to address legal service needs in the future. Despite their lower perception of needs, small counties were least likely (0.0%) to feel that current legal resources could meet anticipated needs while 11.1% of respondents in large counties and 17.9% in medium-sized counties felt confident with current resources.

AIDS social service providers in all of the intensive sites reaffirmed the need for basic and advocacy-oriented legal services. Yet only San Francisco, with BALIF (Bay Area Lawyers for Individual Freedom) and the National Gay Rights Advocates, had low- or no-cost legal services available to persons with AIDS or ARC at the time of the site visit. In the five other intensive sites, AIDS agencies have attempted to maintain referral lists of selected attorneys who will deal with PWA/PWARC legal needs, oftentimes on a reduced fee basis.

In the five counties without legal service programs, persons with AIDS and ARC reported that estate, disability and advocacy-oriented legal concerns often had gone unresolved, largely because of cost considerations. Significant others, in a Sacramento interview group, talked of the symbolism attached to wills, durable medical powers of attorney, living wills and related matters. Addressing these issues often means acknowledging the likelihood of serious disability or death. The decision to take these actions is often delayed and, when it does take place, can create a sizable emotional burden. Most persons with ARC or AIDS and their significant others felt that the need

for legal services represented a crucial support service gap; important legal matters were often left without satisfactory resolution.

### **Income Assistance**

Loss of employment and the resulting decline in personal income was reported by the majority of persons with AIDS and ARC to be the most significant life change associated with their illnesses. An array of government insurance and income assistance programs such as Social Security Disability Insurance (SSDI), State Disability Insurance (SDI), Supplemental Security Income (SSI) and General Assistance (GA) provide varying levels of support to eligible individuals, often well below prior income levels. (SSI pays a maximum of \$560 per month, while the General Assistance level in San Francisco County, for example, is \$303 monthly.) Some PWAs/PWARCs are fortunate to be vested in retirement plans. These individuals reported the least decline in personal income following their diagnoses.

For individuals on General Assistance and SSI, benefits are often insufficient to meet daily living costs in many areas. Particularly at risk are GA and SSI recipients in San Francisco and Los Angeles where daily living expenses, particularly housing, are especially high. Many persons with AIDS or ARC report the periodic need for emergency cash assistance to cover rent deposits, utility and telephone bills, prescriptions not covered by private insurance or MediCal, private insurance premiums, and many other personal and household expenses. In many cases, voluntary emergency assistance programs make an important, though limited, contribution to PWAs' and PWARCs' quality of life by covering selected expenses and meeting special needs not encompassed by other health care and social services programs.

Eligibility for state and federal disability insurance programs is based upon prior payment into the fund by employers and employees for specified minimum periods of time. Individuals who are casually, seasonally or marginally employed may find that their past employment did not provide eligibility for SDI or SSDI. As the epidemic widens, seasonal workers, persons employed in the service sector and poorly paid casual workers will be most at risk for denial of these income benefits and may be forced to rely on GA for subsistence.

Cash assistance programs targeted specifically for persons with AIDS (and usually including persons with ARC) exist in each of the study's six intensive sites. Programs in some areas are administered by agencies focusing exclusively on providing cash assistance (Aid for AIDS in Los Angeles, San Francisco's AIDS Emergency Fund). Multipurpose AIDS service and education agencies also provide cash assistance in some areas (the Central Valley AIDS Team's Fairy Godmother Fund, the Emergency Fund at the Sacramento AIDS Foundation). Charitable and religious groups (St. Joseph's Fund at Catholic Social Services in San Francisco, Holy Trinity Community Church in Santa Clara) also provide cash assistance to needy individuals, including persons with ARC or AIDS.

Cash assistance programs uniformly rely on donations and fundraising events to build cash reserves but many are able to maintain only minimal account balances (e.g., an average of \$300 in the Fairy Godmother Fund), thus restricting the number of persons to be assisted and the average level of assistance provided. Larger programs in urban areas are able to maintain substantially greater cash reserves but must maintain strict benefits limits in order to meet the needs of their larger caseloads. Because of the widespread need for emergency cash assistance in all areas, most programs have established monthly or annual limits for assistance to individuals. The average appears to be in the \$400-500 per year range with some agencies maintaining the flexibility to meet extraordinary expenses.

Persons with ARC or AIDS who participated in group discussions shared very positive feelings toward voluntary cash assistance programs because of their flexibility and their ability to fill gaps left by government income assistance and other programs. The GA and SSI programs were often criticized for their low levels of benefits, complicated and inflexible eligibility criteria (especially for PWARCs) and long waiting periods between initial application and receipt of benefits.

The principal contributor to the need for income assistance is loss of employment. In addition to its clear effect on income and standard of living for many persons with AIDS or ARC, loss of a job because of AIDS or ARC often puts the individual in the confusing and alien "welfare" system for the first time. Employment also retains important symbolic and structural value in most persons' lives. Loss of work, for many PWAs and PWARCs, meant a lowering of self-esteem, a disruption of daily routines and time management and increased social isolation. Yet none of our intensive sites have



effective job counseling or other employment assistance programs for PWAs and PWARCs. Many cited this as a crucial step towards a more positive and healthful approach to living with AIDS or ARC.

### **Dental Services**

Discussion with PWAs/PWARCs and AIDS service providers in six counties identified a widespread and disturbing gap in services to persons with AIDS or ARC. The problem centers on the dental care needs of this population and the apparent unwillingness of dentists to treat HIV-infected patients. With the exception of San Francisco, where dental care for PWAs/PWARCs is provided through clinics at the UCSF School of Dentistry, AIDS service providers and clients alike report that it is nearly impossible to obtain dental care at any cost, and free or low-cost services simply do not exist.

Discussions with PWAs/PWARCs throughout the state indicated that preventive dental care (cleaning, scaling, x-rays) as well as basic dental therapy (fillings, root canals, periodontal work) cannot be obtained, and many persons with ARC or AIDS have gone without needed dental services. In several cases, these problems have become acute and have interfered with proper nutrition.

The problem appears to be twofold. Many dental professionals (dentists, hygienists, assistants) have only limited knowledge of AIDS and HIV transmissibility and, given the amount of contact with blood in many dental procedures, few practitioners seem willing to provide care with this level of uncertainty. Not all dentists are uninformed about AIDS and some could be persuaded to provide service to HIV-infected individuals, but concerns about the reactions of other patients, other providers and the community at large have deterred them from treating PWAs/PWARCs. In Fresno, for example, one dentist will treat persons with AIDS or ARC--late at night or on weekends when his staff, clients and professional colleagues are away from his office. A volunteer from a local AIDS agency serves as the dental assistant at these times, and critically necessary services are provided with considerable secrecy.

This example underscores the dual nature of the dental care problem for HIV-infected persons. As caseloads continue to grow, the need for dental care for this population--often debilitated and frequently without the ability to pay for care--is

expected to become especially acute, and few AIDS service agencies have therefore been able to effectively address this crucial need of persons with AIDS or ARC.

### **Information and Referral**

Identifying and locating health care, supportive services, educational resources and other AIDS/ARC agencies and services can involve a considerable effort on the part of a person with AIDS or ARC or their principal caregivers. Particularly following initial diagnosis, a person with AIDS or ARC often begins to recognize a range of needs and begins to assemble formal and informal supports. Comprehensive, accessible and accurate information on programs and resources available to individuals with AIDS and ARC can greatly expedite this oftentimes complicated and frustrating process. AIDS Information and Referral (I&R) services exist for all California counties to assist asymptomatic HIV-infected individuals, PWAs, PWARCs, significant others and the general public in locating services appropriate to their needs.

A total of 78.3% of respondents in our 20-county survey indicated that I&R services represent a very likely need of PWAs, PWARCs, their loved ones and the public in their counties. Another 17.4% felt I&R to be a somewhat likely need. Perceptions of need varied by county size. Not unexpectedly, in large counties with generally higher AIDS/ARC caseloads and broader arrays of AIDS-related services, 100.0% of respondents saw I&R as a very likely need. Mid-sized counties were next, with 78.6% of respondents reporting this as a very likely need. In smaller counties, generally with fewer service options, 55.6% felt I&R to be a very important need and fully 22.2% of respondents saw no need for such services in the near future.

Only 13.1% of all survey respondents felt that existing I&R resources were adequate to meet anticipated needs. Over half (54.3%) indicated that some new resources and 26.2% felt that many new resources would be required to meet future I&R needs. Respondents from larger counties experienced greater confidence in existing I&R services (33.3% indicated that needs could be met with current resources) than did small (11.1%) or mid-sized (7.1%) counties.

In each of our six intensive sites, information and referral was provided primarily by the AIDS Information and Education contractor (APLA, San Francisco and Sacramento



AIDS Foundations, Central Valley AIDS Team), although virtually all AIDS agencies maintain resource listings and are capable of directing clients to other sources of service.

Group discussion participants felt that effective I&R was an important tool for meeting specific personal needs related to their illness. Existing services were criticized by participants in some areas because waiting times on the telephone were often long, service information was sometimes outdated, incomplete or inaccurate, and I&R staff or volunteers often had too little time to spend per call because of the volume of calls.

The recent publicity surrounding heterosexual AIDS transmission has brought a swell of I&R calls from the broader community to agencies which are frequently gay-identified in the community. Agencies perceive this development positively as an initial step in targeting the entire community for educational efforts and client services.

#### **Case Management/Advocacy**

For many persons with ARC or AIDS, assembling a package of health care and supportive services and identifying, locating and becoming eligible for various benefits and services can be an especially taxing ordeal. This is particularly true for newly-diagnosed individuals working through the emotional impact of the diagnosis, for individuals experiencing debilitation and dementia as a result of their illnesses, and new arrivals to a community. To ensure that needs are met, especially for the most dependent clients, case management represents an important means of accessing and linking AIDS-related programs, benefits and services and ensures the receipt of appropriate types and levels of services as client needs evolve over the course of their illnesses. Linked closely to case management is client advocacy which involves more directed and intensive efforts to appeal eligibility decisions, deal with issues of discrimination or unfairness, and related functions to protect the client and assure his/her basic rights and entitlements.

In the survey of 20 counties, case management was identified by 63.6% of respondents as a very likely need. Another 31.8% identified it as a somewhat likely need. Respondents from larger counties (77.8%) were somewhat more likely to perceive a very likely need for these services than were those from medium-sized (60.7%) or smaller (57.1%) counties.

Case management ranked among the lowest of all services when respondents indicated whether existing services could be expected to meet future needs. Only 6.7% of

all respondents so indicated. Nearly two-thirds (62.2%) felt that some new case management resources would be needed and 22.2% felt that many more resources were required for expected AIDS/ARC caseloads. No respondents in large or small counties felt confident with current case management resources, while 10.7% of those from mid-sized counties reported that expected needs could be met with current resources.

Discussions with AIDS service providers in the six intensive sites suggest that case management is a somewhat different process in different areas. In larger, urban counties with sizable AIDS/ARC caseloads, case management often involves identifying and selecting services and benefits appropriate for the client from a broad array of available, though often overburdened, services. The complexity of the service system, both with respect to the number of agencies involved and the closeness of their connections, can affect the level of difficulty for the case manager as well as the quality of the outcome in terms of creating a service package appropriate to the needs of the client. For example, San Francisco's AIDS support service network involves many agencies and cross-agency case management is gradually expanding to reflect the complexity of the service system.

In smaller suburban and rural areas, case management often involves seeking out sources of services where few appear to exist. With few specialized AIDS service agencies, case managers in these areas often must tap into existing community health and social service resources and facilitate (or advocate for) services to their AIDS/ARC clients. Lack of familiarity with the needs of persons with AIDS or ARC, fear of contagion, and client or community reaction impede the case management function in some areas.

Regardless of its focus, case management is what can help bring services together for PWAs/PWARCs. In San Francisco and Los Angeles, the growth of the women's and minority AIDS/ARC caseloads has encouraged the development of specially identified individuals and services to provide case management and advocacy. These specialized approaches can help to reduce cultural and language barriers to services and can reduce the stress associated with the intimacy of revealing very personal needs and concerns with agency staff or volunteers. Population-specific case management was also reported to facilitate access to specialized women's and minority programs and services which sometimes escape the I&R and general case management services.

## SUMMARY

Persons with ARC or AIDS experience a variety of illness-related changes in their lives, many of which can be addressed by an array of supportive services designed to assist with daily living needs (e.g., housing, hospice, transportation, legal services, income assistance, medication assistance and home health, post-acute care), needs related to maintaining a home (e.g., practical help in the home, home-delivered meals, low-cost or free groceries), and needs associated with identifying and qualifying for supportive services and other benefits (e.g., information and referral, case management, advocacy, legal assistance). Each of these services represents an important support for PWAs/PWARCs as they seek to retain independence, functionality and overall quality of life.

These needs are necessarily unique to the individual PWA/PWARC and will likely evolve over the course of the illness. AIDS/ARC service providers throughout the state have recognized some or all of these needs in their communities and have developed programs and services to address them. Supplementing formal efforts are cadres of volunteers, lovers, family members and friends of persons with ARC or AIDS who frequently step in to provide assistance when organized programs and services are unavailable.

Our discussions with persons with ARC or AIDS, and with providers of AIDS-related services, as well as our survey of providers in 20 California counties, have shown very clearly both the breadth and depth of the physical needs of PWAs/PWARCs and the array of local strategies developed in response to these needs. Here we summarize unmet physical supportive service needs as a way of understanding the next steps which should be taken to adequately support persons with ARC or AIDS throughout their illnesses. It is important to recognize that this analysis of unmet needs is not intended as an assessment of the relative or absolute importance of a particular supportive service. Rather, we discuss current unmet service needs on a statewide basis. As the epidemic reaches deeper into populations of minorities, IV drug users, women, and children, the dimensions of these needs (and the appropriate response of each community's supportive service network) will continue to evolve.

Three ratings are used to describe the relative levels of unmet service needs. A "high" rating refers to urgent, unresolved needs affecting sizable portions of the AIDS/ARC population and requiring immediate attention. High-level unmet needs also

reflect a significant statewide consensus on the immediacy and expressed severity of the unmet service need. A rating of "moderate" refers to important, but not urgent, needs affecting some PWAs/PWARCs and suggests that some level of service is available in some areas of the state. "Low"-level unmet needs are generally those affecting small numbers of PWAs/PWARCs or those for which services are somewhat more available, as needed, in communities across the state.

Resources (both financial and staff-related) needed to respond to unmet service needs are similarly described. "High" levels of new resources reflect the significant cost of providing one or more supportive services in terms of capital and labor expenditures. "Moderate" or "low" levels of new resources may describe circumstances where overall service provision costs are lower, because of the use of volunteers, low capital or labor intensity, or other organizational factors which can achieve economies to keep service costs low. The overall level of resources required to address unmet supportive service needs is clearly dependent upon the approach to service integration. In general, it is far less costly and more efficient to add incrementally to existing service systems than it is to create new, specialized services. Where this issue is significant, a distinction in the expected levels of new resources has been made.

**Housing** represents an important daily living need of all PWAs/PWARCs. AIDS service providers interviewed in six counties identified affordable (market) housing and some forms of attended housing (generally board and care) as critical unmet needs, particularly in the larger urban areas where housing costs are highest. These perceptions of service providers were echoed by persons with AIDS or ARC who emphasized the importance of a stable living situation in managing their illnesses and the seemingly intractable problems associated with locating housing appropriate to their financial and functional status. Similarly, over 90% of respondents to the 20-county survey reported affordable housing as a very likely or somewhat likely service need, although only 2.2% felt that current resources could adequately address anticipated levels of housing need.

Housing, both affordable and attended, currently represents a high level of unmet need across the state for persons with AIDS or ARC. In larger, urban areas, affordable housing and emergency shelter are the principal unmet housing service needs, while in suburban and rural areas, the availability and accessibility of board and care facilities, emergency shelter and group housing for PWAs/PWARCs remain as gaps in the AIDS service network in these communities. Addressing these needs throughout the state is

expected to involve high levels of professional and financial resources, particularly as caseloads grow and new populations with housing needs emerge.

The need for assistance with cooking, cleaning, laundry or shopping is experienced by sizable numbers of persons with ARC or AIDS, particularly during periods of debilitation or dementia. Service providers reported that the current patchwork of in-home support services, provided primarily by volunteers, state-supported IHSS providers and family members, friends and lovers is stretched very thin but appears to be meeting current levels of need in many cases. The exceptions are the urban areas with the highest concentration of AIDS/ARC cases where the sheer magnitude of need can overwhelm even the comparatively sizable formal and informal in-home support resources in these areas. Fully 95.7% of survey respondents highlighted the importance of in-home practical assistance by reporting it as a likely service need. Yet only 13.3% of the respondents felt that existing services would be adequate to address the expected needs of PWAs/PWARCs in their communities. In-home assistance with chores and cleaning was seen by persons with ARC or AIDS as an important means of maintaining maximum possible independence and many throughout the state felt that current levels of service did not adequately meet their needs.

Practical help in the home currently figures as a moderate unmet service need in most communities across the state and one which will require low to moderate levels of financial and volunteer services to address. Resource requirements will necessarily vary by the degree of professionalism involved in the direct delivery of this and other supportive services.

Hospice services, provided in the home or in a hospice facility, appear to be in place in many communities across the state. Service providers reported that formal or informal hospice care is generally available to PWAs/PWARCs during the latter stages of their illnesses. The exception appears to be PWAs/PWARCs who live alone, with no regular source of assistance in the home, a key element of the hospice approach. A total of 93.5% of survey respondents confirmed information from interviews when they reported hospice care as a very or somewhat likely service need for persons with ARC or AIDS in their counties. Nearly one-third (30.4%) of these respondents felt that current hospice resources would be adequate to meet anticipated service needs.

Home-based hospice services, then, currently represent a moderate level of unmet need for PWAs and PWARCs in all areas except those with the highest concentration of

cases where in-facility care is emerging as a high-level unmet service need. Addressing in-home hospice needs will require moderate levels of professional and financial resources in many parts of the state. High levels of new resources will be needed for facility-based hospice services in areas with high, concentrated caseloads.

Persons with AIDS or ARC frequently require assistance with infusions, IV drips and other health care services in their homes. The availability of home health care services often makes the difference between hospitalization or living in one's own home. In each of our intensive sites, home-based care was provided by unique configurations of public health nurses, private home health care agencies and some hospice services. Problems with insufficient allocations of home health hours per client were reported in many sites due to heavy caseloads in the larger, urban counties and reluctance to serve PWAs/PWARCs in some smaller areas. The result in both sets of instances is an underserved AIDS/ARC population which must often rely on daily trips to outpatient clinics or, in some cases, lengthy and costly hospitalizations. Survey respondents also recognized the importance of home health services, with 93.2% indicating this as a likely future service need, yet only 15.5% reported that current home health resources were adequate to meet anticipated levels of need. A sizable number of the PWAs/PWARCs interviewed expressed concerns regarding the limited hours of home health help available through each county's public health department and, to a lesser extent, through private home nursing services generally available to individuals with private health insurance policies. For them, the availability of adequate levels of home health care makes an important contribution to health status and overall quality of life.

Home health for persons with AIDS or ARC is a moderate unmet need but, because of the level of provider skill required, one which will likely require moderate to high levels of additional resources to meet the needs generated by expanding AIDS/ARC caseloads in each county.

Post-acute care, provided in a skilled nursing or intermediate care facility (SNF or ICF), is generally unavailable to persons with AIDS or ARC throughout the state. Facilities of both kinds operate statewide at near total occupancy and, with few exceptions, service providers have not extended their care to the AIDS/ARC population. Fully 93.4% of survey respondents saw the need for skilled nursing care for their anticipated PWA/PWARC caseload but less than one-fifth (17.4%) reported that current facilities could adequately meet those needs. Discussions with PWAs/PWARCs and AIDS



service providers confirmed the lack of available SNF/ICF care and indicated that unnecessarily lengthy hospital stays often resulted from the near total absence of SNF or ICF beds in their areas.

Skilled nursing or intermediate care, provided in a licensed facility, represents a high-level unmet need. The professional and monetary resources needed to meet this need, which will be substantially complicated by rapidly growing AIDS/ARC caseloads, is expected to be very high.

Maintaining independence was identified by PWAs/PWARCs throughout the state as a major life goal, and maintaining a personal residence was viewed as a key element of independence. For persons with mobility problems, **home-delivered meals** are an important resource, available in some, but not all, areas. Similarly, **low-cost or free groceries** can help stretch limited income and provide a base of valuable daily nutrition. This service, too, is not available in all areas of the state. Service providers in areas without one or both of these food services expected that unmet needs, currently at moderate levels, would greatly expand as AIDS/ARC caseloads do, causing a potentially serious nutrition and independence problem.

Limited availability of home-delivered meals and free or low-cost groceries in some cases, coupled with limited allocations per client (one or two meals per day, two bags of groceries per week) suggest that these services constitute a moderate level of unmet need statewide. Because many programs rely on surplus or donated foods and volunteer staff, only low to moderate community resources may be required to adequately address this unmet service need.

Also important to the independence of PWAs or PWARCs is the availability of **transportation** on a daily basis. Organized, volunteer-based services are available in the larger urban areas, but transportation remains problematic for persons with ARC or AIDS in many areas of the state. Liability issues have limited service development in some areas and the level of demand for organized transportation services has meant that health care transit is virtually the only need that can be accommodated in others. Survey respondents (93.5%) identified transportation as a very or somewhat likely service need but only 6.7% felt that current services were sufficient to meet the expected transportation needs (medical and other) of persons with AIDS or ARC. Considerable numbers of PWAs/PWARCs (and virtually all who no longer owned cars or drove)

indicated that unmet needs for transportation affected them at least occasionally and that their independence had been compromised as a result.

Therefore, organized transportation services, volunteers and significant others appear to be meeting a portion of the need in many areas. As caseloads grow, however, transportation will emerge as a moderate unmet need requiring moderate levels of new resources, particularly in the form of liability protection and volunteers.

Persons with AIDS or ARC and AIDS service providers throughout the state reported that legal services were generally unavailable at reduced or no cost. The only formal legal services for PWAs and PWARCs exist in San Francisco, and many individuals were forced to leave important estate, life support and appeals/advocacy legal issues unresolved due to high costs. Legal services were rated near the bottom of AIDS/ARC service needs by respondents to our 20-county survey yet fully 86.7% felt this to be a very or somewhat likely future service need. Only 13% felt confident in the ability of existing services to address expected legal service needs.

These data suggest that legal services currently constitute a moderate- to high-level unmet need which could be met by extending the present reliance on donated legal services (thus requiring only low levels of additional resources) or on formalized legal assistance services for PWAs/PWARCs which would require high levels of new professional and dollar resources.

Income was reported by persons with AIDS or ARC and by their service providers as the most basic and intractable need. Most federal, state and county income assistance programs provide benefits which do not adequately cover the daily living expenses of many PWAs/PWARCs, particularly in larger urban areas where housing and other costs are highest. Emergency cash assistance programs in many areas are successful in meeting short-term, emergency cash needs, but their resources cannot fill even a small portion of the need remaining from GA and SSI benefits levels.

Addressing the pervasive problem of adequate income for PWAs and PWARCs remains a very serious, high-level unmet need which will require high levels of new cash resources and changes in state and federal benefits policies and programs to adequately meet these needs.



Dental services are largely unavailable to persons with ARC or AIDS throughout the state and needed care has been deferred by sizable numbers of PWAs/PWARCs as a result. Dental care, then, is a high-level unmet need which can be addressed with moderate levels of new resources, largely in the form of provider education to encourage expanded provision of dental services to HIV-infected individuals.

Information and referral (I&R) helps to link PWAs/PWARCs with service needs to sources of appropriate care. I&R is currently available at some level in all areas of the state. Reliance on volunteers, badly overburdened budgets, and growing numbers of inquiries have created problems associated with hours of operations, comprehensiveness of coverage and currency of information. The central role of I&R services was recognized by respondents to our 20-county survey, 95.7% of whom saw I&R as a likely service need. Only 13% of these same respondents felt that existing services could adequately meet their county's growing I&R need.

A modest expansion of I&R services represents a low-level service need at the present time in most areas of the state, and we expect that only low levels of new resources will be needed to accommodate such an expansion.

Locating and bringing together services and benefits for persons with AIDS or ARC are the principal functions of **case management** and **advocacy** services. Some form of these services is in place in each of the study's intensive sites but much is volunteer-based and professional staff-to-client ratios are now far in excess of what might be considered appropriate for effective service. Despite variations in service availability across the state, case management and advocacy generally are not adequate for the needs of PWAs/PWARCs in most areas of the state. The important function of effective case management was recognized by survey respondents, 95.5% of whom reported it as a likely service need in their county. Also according to this group, current resources cannot be expected to meet the case management or advocacy needs of expected AIDS/ARC caseloads. Only 6.7% of respondents felt confident in current levels of service.

Case management and advocacy remain moderate- to high-level unmet service needs for the AIDS/ARC population. Addressing this need will require a moderate level of new professional and monetary resources across the state.

Each of the services identified in this chapter is intended to address the physical needs of persons with AIDS or ARC. At some level, each represents a current unmet need

5which is expected to become exacerbated by the relentless increase in each county's AIDS/ARC caseload and for which some level of new resources will be required. The rankings are intended to be interpreted in relative terms as a means of prioritizing needs and appropriate county and state responses.

## **CHAPTER FOUR**

### **PSYCHO-SOCIAL SUPPORTIVE SERVICE NEEDS**

#### **INTRODUCTION**

This chapter continues the analysis of the supportive service needs of seropositives, persons with ARC and persons with AIDS. In the preceding chapter, the discussion assessed AIDS-related physical needs and service responses, while in this chapter we address psycho-social needs and services. Once again, we draw upon information provided by AIDS service providers, other community-based supportive service agencies, persons with ARC or AIDS, and their caregivers. Data from the 20-county survey also provided valuable insights into expected psycho-social needs and current service capacities. See Appendix E for the combined survey data. This chapter includes an analysis of the psycho-social needs of caregivers (family members, friends, volunteers) because of their key role in providing support to PWAs/PWARCs and the emotional burden often associated with their caregiving activities.

#### **SERVICE NEEDS**

##### **Psychological Counseling**

The phrase "psychological counseling services" encompasses a wide variety of therapeutic orientations and modalities. Often referred to as "therapy," such services typically are of time limited duration and emphasize ways of understanding and coping with current emotional problems. Counseling services may be directed at the individual, couple, or family, according to the nature of the problem and the availability and willingness of individuals to participate in treatment. Formal sessions may occur weekly or more frequently depending on the needs of the client. Psychological counseling services may have applicability at numerous points in the AIDS infection continuum, from the antibody testing stage, to determination of seropositivity, to diagnosis, and ultimately through the dying process.

At its core, psychological counseling differs from other methods of emotional support in that the service is provided by a trained, and often licensed, professional. Therapists active in offering psychological counseling may be licensed as Marriage, Family, and Child Counselors (MFCCs), clinical social workers (LCSWs), or clinical psychologists. Such providers may be agency-based or in private practice.

The need for this kind of service is documented by the responses to the mail survey. Fully 87% of those responding rated psychological counseling as a very likely service need for PWAs/PWARCs in their counties, and an additional 8.7% considered such services as a somewhat likely need. Psychological counseling services, in fact, were the second most frequently cited service need, following just behind the need for emotional support groups.

Perceptions of the need for this type of service varied somewhat according to the size of the county. While all of the respondents from large counties (i.e., those with populations over 500,000) rated psychological counseling as a very likely service need, 85.7% of those from medium-sized counties (i.e., those with populations between 100,000 and 500,000) and 77.8% of those from small counties (i.e., those with populations less than 100,000) viewed the need for these services as very likely. More importantly, over a fifth (22.2%) of those from small counties perceived the need for psychological services as not likely, whereas none of the respondents from either large or medium-sized counties gave that rating.

Although recognizing the importance of these services, only 19.6% of the respondents across the state indicated that psychological counseling needs could be met with current resources. Over half (52.2%) reported that some new resources would be needed and almost a quarter (23.9%) felt that many new resources would be required. Respondents from medium-sized counties were somewhat more likely than were their counterparts from either large or small counties to feel that psychological counseling service needs could be met with existing resources (25% vs. 11.1% vs. 11.1% respectively). Almost a quarter of those from each type of county indicated that many new resources would be necessary, and slightly more than half of the respondents from medium and large counties and 44% of those from small counties felt that some new resources would be needed. Almost a quarter of those from small counties, however, did not know if these service needs could be met with present resource or if new resources would be necessary.

The general importance assigned to psychological counseling services by the survey respondents was echoed and reaffirmed by our discussions with providers at the six sites visited during the study. Reports of increasing AIDS-related central nervous system disorders and dementia have heightened the need for professional psychological assessments and screenings, particularly in those counties with greater caseloads. At each of the sites, however, service providers described the importance as well as the difficulty in securing psychological counseling for PWAs/PWARCs. Barriers to obtaining such services include: cost, and particularly the reimbursement level provided under MediCal and MIA coverages; provider reluctance to accept PWAs/PWARCs; and the lack of providers who are both familiar and comfortable with the kinds of issues which PWAs/PWARCs may need to resolve.

Although often difficult to obtain, many of the AIDS agencies we visited have attempted to implement strategies to ensure that the psychological counseling needs of their clients are met. For instance, the Sacramento AIDS Foundation (SAF) has identified private practitioners in the county willing to work with PWAs/PWARCs, and the SAF will assume the cost of counseling sessions for up to six weeks. In San Francisco, private practitioners are being encouraged by their colleagues to provide services to PWAs/PWARCs on a pro bono basis. These efforts are being encouraged by the San Francisco AIDS Foundation, and lists of counseling providers are maintained for referral use. Another strategy is that of the AIDS Project of Los Angeles (APLA) which is attempting to establish its own mental health clinic to meet the counseling needs of its clientele.

Our discussions with PWAs/PWARCs brought into sharp relief the importance of psychological counseling services. Many of those interviewed stated that they would like to receive professional counseling. Although almost all participated in some form of support group and/or had an "emotional support buddy," the PWAs/PWARCs we met recognized the limitations of these informal sources of emotional assistance. Several gave examples of specific issues which they felt reluctant to discuss with their peer "supporters." Those interviewed expressed strong desires to receive professional guidance for certain sensitive or particularly problematic issues. It is particularly disheartening to note that few of the PWAs/PWARCs with whom we spoke were able to obtain the psychological counseling assistance they needed.

## Emotional Support Groups

Emotional support groups have gained widespread use within the past few decades for numerous psycho-social issues. Emotional support groups bring together individuals who share common problems or concerns so that they can share as well as learn from each others' experiences. To a great extent, it is felt that only those who face similar problems or have gone through similar experiences can truly understand an individual's present emotional and situational conflicts. While many emotional support group models use a professional as the group leader or group facilitator, the emphasis within the groups is on developing and promoting a "peer culture." A major thrust of these groups, and hence the centrality of the concept of peers, is to break down feelings of isolation, to help the individual to realize that s/he is not the only one with these concerns. In general, therefore, a major feature of these groups is their non-judgmental and often non-directive approach.

The perceived centrality of emotional support groups to the provision of supportive services to people with AIDS and ARC is an important finding of our needs assessment mail survey. This type of service was most frequently considered to be a very likely service need by respondents across the state, with fully 91.3% so reporting. As with the perceived need for psychological counseling services, those from large and medium-sized counties more often cited this as a very likely need than did those from small counties. All of those from large counties and 92.9% of those from medium-sized counties viewed emotional support groups as a very likely service need of PWAs/PWARCs. In contrast, approximately three-quarters (77.8%) of those from small counties cited this as a very likely service need and a just less than a quarter (22.2%) rated this as an unlikely service need.

Almost a third (32.6%) of the respondents from around the state believed that this service need could be met with existing resources, while just under a half (47.8%) felt that some new resources would be needed and 13% believed that many new resources would be required. Respondents from large counties were less optimistic than were their counterparts from medium and small counties regarding their capabilities to meet the need for emotional support group services with current resources (22.2% vs. 42.9% vs. 44.4% respectively). Similar proportions of those from large and medium-sized counties felt that some new resources would be necessary (44.4% and 42.9% respectively). Fully a third of the respondents from the large counties reported that many new resources would

be necessary, whereas only 14.3% of those from medium-sized counties identified the need for many new resources. Equal proportions of the respondents from the smaller counties reported the need for some new resources, many new resources, or not knowing whether new resources would be needed (22.2% each).

Emotional support groups were an active and vital part of the AIDS/ARC service networks at each of the sites visited. In many cases these support groups were initiated by and connected to the local AIDS service agencies. Providers from different sectors of the service delivery system were in agreement as to the value of these groups, particularly given the difficulties in securing psychological counseling services. The emotional support groups were seen as offering asymptomatic HIV-infected individuals, PWARCs, and PWAs a safe environment within which to explore their feelings, develop survival strategies, and receive support for their actions. While the primary purpose of these groups is to offer peer support, some providers indicated that the groups fulfilled other functions as well. Attendance in these groups was seen as providing some individuals with limited external structure for their lives. For others, the groups afforded them an opportunity to have social interactions; and for some, participation provided a mechanism for enhancing their feelings of self-worth and competency, particularly in instances where they could "advise" newer members on certain topics.

The emotional support groups occurring at the sites reflect a variety of forms and interests. The majority have a professional or trained volunteer, often representing the local AIDS agency, as the facilitator. Most meet on a weekly basis. In Los Angeles, for example, the Shanti Project and APLA have sponsored support groups for several years and numerous groups operate at any given time. New emotional support groups have emerged to address the specific needs of women, Spanish-speaking individuals, and Blacks. Some of these newer groups have been initiated by AIDS projects which focus on these populations, such as the Los Angeles Women's AIDS Project or the El Centro Human Services Corporation, while others have been developed by the more established AIDS service agencies. In addition to emotional support groups for individual PWAs/PWARCs, Los Angeles and San Francisco have couples groups available for PWAs/PWARCs and their significant others.

At several sites, emotional support groups also were available for HIV-infected individuals. In Sacramento, for example, a HIV-positive support group is sponsored by the Sacramento AIDS Foundation. This support group is viewed, according to providers,



as being an important health-promoting mechanism, assisting individuals in expressing and managing their fears and in promoting a more positive future orientation. Support groups such as this are seen as filling the service void which may occur subsequent to the post-testing counseling available at the Alternative Test Sites (ATS).

The vast majority of PWAs/PWARCs interviewed participated in and felt positively about the emotional support groups. They reported receiving a great deal of encouragement and understanding in sharing their concerns with others who were going through similar experiences. Participants indicated that a great deal of practical information and assistance was also shared within the groups. More "experienced" PWAs/PWARCs often would share their knowledge about services and benefits, and would act to "mentor" newly diagnosed PWAs/PWARCs through application and eligibility processes. While several indicated that the groups could not fully meet their emotional/psychological needs, they did not necessarily view this as a limitation of the groups. Rather, they felt that the groups were successfully fulfilling a certain role and that other needs they experienced required a different, more professional form of intervention.

### **"Companion" Support**

Companion support refers to the use of trained non-professionals, often volunteers, to provide regular and ongoing individual emotional support. In this context, companion support frequently takes the form of a "buddy" program wherein a trained volunteer is matched with a PWA/PWARC by staff at the AIDS service agency. The buddy, or companion, typically is required to make a commitment for a specified period of time and/or a designated number of hours per week. This form of "contracting" is undertaken to minimize turnover or other disruptions in the relationship between the buddy and her/his match.

A principal function of companion support is to provide a "sympathetic ear" to the individual PWA/PWARC; buddies listen to and talk with the individual, and provide him/her with a regular source of human companionship and interaction. In contrast to the other methods of emotional support described above, buddies typically go to the individual rather than requiring the PWA/PWARC to travel to some central site. Thus, companion support is especially valuable for those PWAs/PWARCs who may be most at

risk of isolation--i.e., those experiencing mobility problems, those with disfigurement, or those who are bed-ridden.

Variants of the buddy model were evidenced at each of the sites visited. The Shanti Project of San Francisco, which was one of the first organizations in the country to apply a companion support model to PWAs/PWARCs, is the primary locus for such services in the City. Hundreds of volunteers are trained each year by Shanti staff. These community members provide thousands of hours of service to PWAs and PWARCs. The Los Angeles Shanti Project also maintains an extensive and active emotional support buddy component. Companion support is also available through APLA, which additionally uses the buddies as informational and monitoring intermediaries between the clients and the case managers. In Santa Clara, Sacramento, and Riverside Counties, the buddy support programs offered by the AIDS agencies represent a primary feature of the supportive service systems.

The service providers with whom we spoke were unanimous in their endorsements of companion support services. Several providers indicated that the volunteer buddies, in fact, acted as the major service providers in the sites. Given the resource constraints faced by many of the AIDS service agencies and the growing caseloads of PWAs/PWARCs, buddies represent for many organizations a critical method of "staffing." This was true in the two large metropolitan areas as well as in the four other sites visited.

Across the six sites, many of the PWAs/PWARCs interviewed positively discussed their relationships with their buddies. For the affected individual, the buddy often served as his/her contact with the "regular" world. The development of strong friendships were frequently depicted as growing out of the buddy matches. Buddies were viewed as important confidants and conversational partners. Some individuals, however, indicated a reluctance to discuss certain topics with their buddies or feared burdening them with issues which were "too heavy."

Often emotional support buddies fulfill a number of functions in their matches' lives in addition to their roles as "listeners." We had the opportunity to talk with an emotional support buddy from the Desert AIDS Project in Palm Springs who movingly described his relationship with his match. The PWA in this instance did not have an extensive personal support system of friends or family members in the area. As he became increasingly debilitated, the buddy took on a central caregiving role. In addition to emotional support, the buddy acted as his advocate, assisting him in applying for

benefits, completing legal documents, and delivering forms to appropriate agencies. He made sure that there was food in the house and frequently prepared meals too. The buddy often picked up prescriptions for the individual and performed numerous other errands as well. As this example illustrates, volunteer emotional support buddies may expand their roles to provide the type of individualized caregiving which presently is unavailable from other, more formal service sectors.

It is clear from our discussions with providers, PWAs/PWARCs, and volunteers that emotional support buddies play a critical role in the AIDS service networks. To date, problems in the use of buddies have been resolved without many difficulties-- "mismatches" have been remedied and new volunteers have been introduced as more experienced ones "burn-out." Yet questions are starting to arise regarding the long-term viability of this model as a central service delivery mechanism. First, the pool of potential volunteers may be diminishing somewhat, particularly in areas where the majority of volunteers have come from the gay community and may themselves be at risk of or are experiencing HIV infection. Second, the characteristics and needs of potential clients are changing as the virus spreads into other population groups. Women with children, minorities, and IV drug users often present a range of service needs that are more complex and more difficult to meet. Informal discussions in the Sacramento area illustrated the difficulties that buddies may have in serving these "new" clients. One individual, who was matched with an IV drug user, described his feelings of frustration in working with this often unpredictable and demanding PWA. Although he had previously worked successfully as a buddy to gay men with AIDS, he felt he could not handle his present match and was contemplating asking for a reassignment.

### **Emotional Assistance for Family Members**

Family members of PWAs/PWARCs may need a variety of forms of emotional support over the course of their loved ones' illnesses, and even after their deaths. Whether the "family" is defined as the family of origin (i.e., parents, siblings, or other relatives) or the family of orientation (i.e., partner/spouse, children, or other adults with whom the individual maintains close ties), these individuals may experience significant stress in caring for a PWA/PWARC. Witnessing the deterioration of a loved one also may cause family members' feelings and fears about their own mortality to surface, and reactions may be further exacerbated when there is a possibility that the family member

also may have been exposed to HIV infection. And family members often need emotional support and assistance to cope with the deaths of their loved ones.

Emotional assistance may take the form of formal psychological counseling, emotional support groups, spiritual counseling, or grief counseling. As with emotional support groups for PWAs/PWARCs, support groups for family members may be organized around particular issues or interests such as partners/spouses, parents of adult children, parents of young children and adolescents, children of infected parents, etc. Regardless of their particular form, services providing emotional assistance frequently are viewed as crucial to supporting family members in their caregiving roles.

When asked in the mail survey to rate the likelihood of the need for this type of service, approximately three-quarter of the respondents (76.1%) indicated that it is a very likely service need and almost a fifth (19.6%) described it as a somewhat likely need. Differences in the perception of the need for these services are found in relation to county size. All of those responding from large counties cited emotional assistance for family members as a very likely service need, while slightly more than three-quarters (78.6%) of those from medium-sized counties and less than half (44.4%) of those from small counties gave that rating. A fifth (21.1%) of those from medium-sized counties suggested that these services would represent a somewhat likely need. In contrast, a third of the respondents from small counties identified the need for family emotional assistance as somewhat likely, and fully a fifth (22.2%) described this as an unlikely need.

Almost a third (32.6%) of the respondents statewide believed that this service need could be met with existing resources, while almost a half (47.8%) felt that some new resources would be needed and 13% believed that many new resources would be necessary. In a pattern similar to that found with psychological counseling, respondents from medium-sized counties more often reported that current resources could meet this service need than did those from either large or small counties (46.4% vs. 11.1% vs. 11.1% respectively). Two-thirds of those from large counties, more than a third (39.3%) of those from medium-sized counties, and over a half (55.6%) of those from small counties reported that some new resources would be required to support these services. Approximately 10% of the respondents from each type of county indicated that many new resources would be necessary.

Service providers at the six sites reported that, along with volunteers, family members typically provide the bulk of care to PWAs/PWARCs. In some instances

PWAs/PWARCs have returned home to their families of origin, while in other cases adult family members have rallied to provide caregiving in the PWA's/PWARC's home. Yet such caretaking can be a round-the-clock, seven day a week job, often placing great strain on the family member's own employment and other responsibilities. Family members further may find themselves increasingly isolated from other social contacts and activities. Physical exhaustion may occur as well. The economic devastation experienced by many PWAs/PWARCs also may extend to their families. And running throughout all of this is the emotional pain of witnessing a loved one suffer and die.

Concern for the well-being of family members was manifest at each of the sites we visited. A "significant others" support group was the service most commonly offered by the AIDS service agencies to meet the emotional assistance needs of family members. Special groups for family members and friends focusing on the grieving process tended to be available in the larger sites visited. Some projects, such as the Sacramento AIDS Foundation and the Central Valley AIDS Team, have, at times, maintained contact with family members whose loved ones have died and over time have encouraged these individuals to become active in assisting new families to cope with the crisis of AIDS.

A unique perspective on the needs of family members was offered by a Los Angeles provider who is working with the families of pediatric AIDS cases. In some respects, the emotional devastation experienced by parents of young PWAs/PWARCs may be even greater than that experienced by parents of adult children. These parents frequently are isolated both from others like themselves and often from their usual sources of support. The stigma associated with AIDS may prevent these parents from revealing to their friends and neighbors the precise nature of their child's disease. This provider reported that these parents had significant needs for counseling and emotional support services, many of which are not being effectively met.

A group discussion for family members was conducted during our Sacramento site visit. These individuals graphically described a range of effects that caring for PWAs has had for them. One mother, whose son had returned to his family's home after diagnosis, spoke of the multiple issues she and her husband were forced to initially confront, including the fact that their son was gay, that he was quite ill, and that he was going to die. She illustrated how the social stigma attached to an AIDS diagnosis can effect the whole family--her husband, who works in a food-related industry, was fearful of losing his job if it became known that a person with AIDS was living in his home. He therefore

did not want anyone outside of the immediate family to know of their son's diagnosis, or even of his return. The partner of a PWA echoed these feelings of isolation; in his situation, the stigma of homosexuality combined with that of AIDS. The affected partner, who had been a successful professional, requested that his diagnosis not be revealed to anyone for fear that his reputation would be tarnished.

Family members spoke as well of the physical exhaustion they experienced in caring for their loved ones. Particularly as an individual becomes sicker and/or if forms of dementia are present, caregiving can become an all encompassing task. Participants also described the helplessness and frustration they felt in fighting what is essentially a "losing battle"; no matter what they did, no matter how hard they tried, their loved ones would not get better. A mother spoke of the unfairness of the generational reversal of this disease--it was in some way fundamentally wrong for her son to die before her. As the discussion was ending, the participants started to talk among themselves and compare their use of alcohol and prescription medications. It emerged that for almost all substance use had become a common method of coping.

Family members spoke warmly about the emotional support group they attended. For several it provided a unique and safe environment for them to acknowledge and discuss what was occurring in their lives. They also learned many "tricks of the caregiving trade," such as where and how to apply for benefits and what legal steps should be taken, from more experienced others in similar situations. One partner, who recognized his need for individual professional counseling to supplement the support of the group, described the difficulties he had in locating such assistance. In addition to cost factors, he was very concerned about confidentiality--public knowledge of his situation could, he felt, jeopardize his career. Moreover, he could not locate a counselor who was knowledgeable about and responsive to AIDS-issues.

### **Respite Care**

Respite care involves the provision of practical support to family members. Typically, an arrangement is made whereby someone comes into the home to relieve the caregiver for a specified period of time, which may range from several hours to a full day to overnight. Respite services allow the family member to refresh and rejuvenate her/himself without having to worry or feel guilty about "abandoning" the sick loved one.



Thus, although practical in form, respite services are integrally tied to fostering the emotional well-being of family caregivers.

A shortage of sources of formal respite services was found at all of the sites visited. Those we interviewed recognized the benefits of respite services to family members. Providers indicated, however, that it was difficult to obtain "traditional" respite care, and often volunteer buddies were used to fill this gap.

The Sacramento family members' discussion group further highlighted the need for respite care. Several individuals reported that they worried whenever they had to leave their loved ones unattended. Moreover, as their social worlds narrowed to that of the "sick bed" during the progression of their loved ones' illnesses, their feelings about leaving home became even more conflicted. To maintain their own sense of self they knew they had to get out at times, but often found it difficult to relax when they did. The availability of a respite care worker would have minimized some of the anxiety they felt.

#### **Help with a Drug or Alcohol Problem**

Assistance with a drug or alcohol problem may take a variety of forms depending on the type of substance used and the severity and longevity of the problem. Services can involve detoxification under medical supervision, chemical maintenance, structured living programs, out-patient counseling, or support groups. Within the context of AIDS-related supportive services, these types of services can hold a variety of meanings: individuals who presently are intravenous drug users may need an array of services different from those who are former users; current or past alcoholics may require another group of services; and, the service needs of "recreational" drug users may differ as well.

More than a third (37.0%) of the providers who responded to our mail survey believed that services designed to help individuals with drug or alcohol problems would be a very likely need. Half thought that such services would be a somewhat likely need and 13.0% indicated that they did not think this would be a likely need for the affected population. As with several of the other psycho-social service areas, perceptions of the likelihood of the need for alcohol and drug services varied in relation to county size. Thus while more than half of those from large or small counties identified these service needs as very likely, only a quarter of the respondents from medium-sized counties gave that rating (55.6% vs. 55.6% vs. 25% respectively). Those from medium-sized counties,



however, more often rated assistance with alcohol and drug problems as a somewhat likely service need than did respondents from either large or small counties (60.7% vs. 44.4% vs. 22.2% respectively). These services were rated as a not likely need by 14.3% of the respondents from medium-sized counties and 22.2% of those from small counties; none of the respondents from large counties reported that these services were not likely to be needed.

In terms of their abilities to meet potential client needs for drug and alcohol services, almost a third (32.6%) of the providers statewide felt that such service needs could be met with existing resources, 41.3% felt that some new resources would be required, and a fifth (19.6%) believed that many new resources would be necessary. Respondents from small and medium-sized counties more frequently reported themselves to be able to meet such service demands with present resources than did those from large counties (33.3% vs. 35.7% vs. 22.2% respectively). Fully 44.4% of those from large counties, 42.9% of those from medium-sized counties, and a third of those from small counties reported that some new resources would be necessary. Respondents from large counties were more likely than their counterparts from either medium or small counties to perceive a need for many new resources (33.3% vs. 17.9% vs. 11.1% respectively). Moreover, a fifth (22.2%) of those from small counties and 3.6% of the respondents from medium-sized counties were unsure of the level of resources that might be required to meet the drug and alcohol service needs of this population.

Issues related to drug and alcohol use, to some extent, represent a relatively newer area of concern for many of the AIDS service agencies that we visited. Many of these organizations, which emerged out of the gay community as a response to the needs of affected gay men, are coming to realize that alcohol and drug use treatment, including that for intravenous drug use, may be germane to their clientele. Providers told us of individuals who had started using drugs or alcohol, often after years of abstinence, in reaction to their antibody test results or diagnoses. And some clients have untreated alcohol or drug dependencies which makes supporting them during their AIDS crisis very difficult.

Another perspective on these needs is provided by agencies whose historical work has been in the areas of drug or alcohol treatment. In contrast to the AIDS agencies which are beginning to recognize substance abuse issues, substance abuse treatment agencies are becoming more attuned to AIDS-related issues. In Sacramento, for example,

staff at a community-based drug treatment program with whom we spoke indicated that they have in-service training on AIDS-related issues for other staff in the agency. They also have begun to encourage their clients to undergo antibody testing. These staff members provide extensive pre- and post-test counseling, and typically accompany their clients during the test process. This agency is also willing to accept PWAs/PWARCs in their out-patient counseling services, in their support groups, and in their residential treatment program. Similarly, in Los Angeles, El Centro Human Services Corporation, which provides mental health services, has recently initiated outreach activities and counseling groups for Spanish-speaking intravenous drug users in East Los Angeles.

Few participants in our group interviews discussed issues relating specifically to drug or alcohol problems. These topics did arise, but for the most part individuals indicated that they had been able to secure assistance from an agency. In our Palm Springs group, however, participants strongly underscored the importance of and need to address these issues. One PWA indicated that there are two aspects that must be understood: first, there needs to be heightened recognition within the AIDS service networks regarding the possibility that clients may have drug or alcohol problems; and second, supportive services, including substance abuse treatment and support groups, must be made available. As a recovered alcoholic, this individual felt that providers often overlooked his need for support in this area. Yet he found his commitment to sobriety often severely tested by the stress of having AIDS. Although he was able to find support in an AA group, he felt that many others might not be as lucky.

### **Adult Day Care**

Several different models exist of adult day care services and these have been used extensively with other vulnerable populations such as the elderly or those with developmental disabilities. Essentially, adult day care involves a range of non-residential activities which are provided at a central site. Models may include occupational therapy, vocational therapy, and recreational or social activities.

Adult day care services can fulfill two distinct functions. For the person attending such programs, adult day care can offer structure, human contact, and intellectual and emotional stimulation. Feelings of self-worth and competency can be greatly enhanced by participation, which in turn can promote one's general health status and sense of well-

being. For the individual's caregiver, adult day care programs act as a source of respite. The caregiver is relieved of his/her caretaking responsibilities for a specified period of time, while knowing that the loved one will be adequately attended to and monitored.

None of the sites visited had adult day care services available for PWAs/PWARCs. In our group interviews, however, participants reported having a great deal of interest in this kind of service. Many indicated that the change from being an "active adult," with regular activities and responsibilities, to a "sick adult," without a routine schedule or set of activities, was one of the most difficult transitions they had to make. To be able to attend a program such as adult day care represented for them a rejection of their label as a "sick" person. By minimizing this label, they felt, they could continue to make a contribution to society as a "productive" adult. It is not surprising, therefore, that many participants expressed a strong desire for vocational, recreational, and social activities.

### **Child-Related Services**

The generic category "child-related services" reflects a wide variety of services for children and their family members. Included within this category are services such as day care, instructional and school-related services, play therapy or other forms of emotional support, foster care, and adoption. These services may be applicable to children who are HIV-positive, those who have ARC/AIDS, or youth who are not infected but whose parent(s) is.

Although childhood AIDS cases are still rare in California, they are not unknown to our state. Moreover, many are looking to the experiences of East Coast cities, such as New York, Newark, and Miami, as an indication of what the pediatric AIDS future may hold. In addition, California has an unusually high proportion of individuals, including children, with hemophilia, in part because of the leadership the state has taken in providing medical support to these individuals. Unfortunately, many hemophiliac children may be at risk of HIV infection from blood transfusions which occurred before 1985; these children and adolescents may over time require extensive assistance.

Several counties are attempting to formulate foster care and adoptions guidelines for pediatric AIDS cases. At the county level, Child Protective Services, within the Department of Social Services, has taken the lead in developing these plans. These developments are most apparent in the more metropolitan counties, such as San Francisco

and Los Angeles. In general, however, there are few services directed specifically at children or adolescents in the state at the present time. While some providers at the AIDS agencies acknowledged the need for such services, particularly day care and after-school care, they reported that they were not seeing a sufficient number of cases to warrant the development of formal programs. Typically, supportive services for children and their families now are available through a loose patchwork of informal and voluntary efforts.

## SUMMARY

The impact of a determination of HIV seropositivity or a diagnosis of ARC or AIDS clearly carries with it significant emotional stress for the diagnosed individual and often for family members as well. Like physical needs, psycho-social burdens require various types of sensitive support throughout the course of the illness. Such supports have been organized in most areas with even modest AIDS/ARC caseloads yet crucial gaps remain. Because psychological health is a critical component of overall well-being, the needs for psycho-social support services must be as carefully considered as are health care and physical support service needs.

Psychological counseling represents the most intensive of psycho-social supports. Persons with AIDS or ARC throughout the state reported the need, largely unmet, to discuss particularly sensitive or problematic issues associated with their illnesses with a trained therapist. This need was underscored by virtually all service providers who we interviewed and by 95.8% of survey respondents who viewed psychological counseling as a very or somewhat likely service need. About one-fifth (19.6%) of these respondents felt that current counseling resources could respond to anticipated levels of need. Discussions with service providers in six counties indicated that few low- or no-cost programs offering psychological counseling to PWAs, PWARCs or seropositives are currently in place. Agencies have assembled resource directories and have attempted to encourage volunteer commitments from professionals but services to clients do not even approximate the existing level of need. As caseloads grow and diversify, the level of unmet need is expected to expand in a significant manner.

One-to-one psychological counseling represents a high level of psycho-social support service need. Given the high level of professional training required to provide this service and the historical difficulty experienced by AIDS agencies in attracting sufficient

voluntary time commitments, we expect that high levels of new resources will be needed to address the psychological counseling needs of PWAs/PWARCs throughout the state, both current and anticipated.

**Emotional support groups** are a key element in the AIDS/ARC service system in each of the six counties visited for this study. Service providers, persons with AIDS/ARC, seropositives and loved ones of PWAs/PWARCs felt strongly about the role of emotional support groups in meeting basic psycho-social support needs. Survey respondents agreed, with 95.7% indicating this as a likely need and fully 91.3% of respondents (the highest percentage for any service) indicating emotional support groups as a very likely need for PWAs/PWARCs in their counties. Only a third (32.6%) of these respondents felt that existing resources would be adequate to meet anticipated needs. AIDS/ARC service providers, however, and clients felt especially strongly about the need for these groups given difficulties obtaining low- or no-cost psychological counseling. Currently, emotional support groups are in place in most areas for PWAs/PWARCs; in some areas for seropositives and in a few areas for family members. Most service providers felt that to adequately address psycho-social needs, these support groups should be routinely available to each of the populations noted above as well as for emerging AIDS/ARC populations with special support needs, particularly women, ethnic minorities and IV drug users.

Addressing the emotional support group needs of the entire AIDS/ARC/seropositive population and of their families in an equitable way represents a low-level unmet need currently but this will grow to a moderate unmet need as caseloads grow, particularly in the women's, minority and IV communities. Resources required to meet these needs are expected to be relatively low as compared to more resource- or staff-intensive services.

**Companion (or "buddy") support**, like emotional support groups, is a key element in the AIDS/ARC service network in most areas. Volunteer companions provide both practical and emotional support, usually following lengthy training and under the supervision of an AIDS service agency staff member. In many areas, volunteer companions represent the primary feature of the AIDS/ARC support service network. In areas with comparatively high caseloads, available "buddies" are becoming more scarce as the number of cases grows and the pool of volunteers appears to be running out. Some areas have reported that finding buddies for "difficult" clients, particularly individuals

with untreated drug or alcohol problems, has been problematic and the magnitude of this problem is expected to worsen significantly in the near future.

Currently, companion programs represent a low-level unmet need, likely to become a moderate need shortly. Low to moderate levels of new professional, volunteer and monetary resources will be required statewide to begin to address this important psychosocial need.

The emotional impact of the illness can be as devastating for family members as it is for the PWA/PWARC. **Emotional assistance for family members** may take the form of psychological counseling, support groups, spiritual assistance or grief counseling. Urban areas with larger AIDS/ARC caseloads offer emotional support groups for family members as a key service component, but smaller areas have not yet developed programs for these individuals. The importance of this service was reported by service providers and PWAs/PWARCs alike and was supported by the results of the 20-county survey, where 95.7% of respondents indicated that emotional help for family members was a likely service need. Nearly one-third (32.6%) of respondents felt confident with existing resources for anticipated needs, with three-fifths (60.8%) indicating the need for additional resources in their areas. The importance of providing emotional support to the families of PWAs/PWARCs is underscored by our observation that, in addition to volunteers, lovers and family members often provide the bulk of supportive care to persons with AIDS or ARC. The dual role of caregiver and loved one can create significant stress, often requiring ongoing support.

While emotional help for family members is available in larger areas, it remains a moderate unmet need on a statewide basis and one which should require only low levels of additional professional resources to address.

Respite care provides "time off" for loved ones caring for a person with ARC or AIDS. Service providers and PWAs/PWARCs emphasized the importance of respite in preventing caregiver "burn-out" and in reducing the overall emotional toll on the family member. Respite care is absent throughout the state despite its perceived need and, in some areas, volunteer companions were used to fill this gap. Respite, then, is a moderate-to high-level unmet need throughout the state, but one in which volunteers could be utilized effectively, thus requiring only low levels of new resources to provide sufficient coverage to address current and future needs.



Services to help with a drug or alcohol problem may involve detoxification, chemical maintenance, structured living programs, counseling or support groups. These services are generally available throughout the state, although as with other services, many are severely overtaxed. All are principally focused on drug abuse, and some have offered or provided services to persons with ARC or AIDS. In our survey of service providers in 20 counties, fully 87.0% felt that substance abuse services constitute a very or somewhat likely service need for their county's AIDS or ARC population, but less than one-third (32.6%) reported that current treatment resources could meet expected future AIDS/ARC needs. Few AIDS service agencies provide substance abuse services. Rather, linkages are forming with the alcohol and drug treatment sectors to expand services to persons with HIV infections. Currently, this area represents a comparatively moderate unmet service need. Most AIDS substance abuse providers felt that compassionate, quality treatment for PWA/PWARC drug abuse would require moderate to high levels of new resources, largely in the form of added education and training for counselors and case managers. The broader availability of alcohol programs in most communities suggests that low to moderate levels of new resources would be required.

Adult day care services fulfill important social and emotional needs of PWAs and PWARCs and act as a form of respite for caregivers. These services are not currently available to persons with AIDS or ARC in the state and represent a moderate-level unmet service need. Expansion of existing respite services to include PWAs/PWARCs would require low to moderate levels of new resources while creation of AIDS/ARC-dedicated services would likely involve moderate to high levels of new professional and monetary resources.

As growing numbers of children are found to be HIV-infected, services to children are expected to emerge as important service needs. Such services may include: day care, instructional and school-related services, play therapy, foster care and adoption. Currently, few linkages exist between the AIDS/ARC service network and organizations providing services to children, except in the larger urban counties with the largest AIDS/ARC cases involving children. As the numbers of children with HIV infection grow, this current low-level unmet need will grow to a moderate unmet need and resource requirements to fill these needs (largely in the form of enhanced coordination and modest service expansion) will likewise grow from low to moderate.



Some forms of services to address the psycho-social needs of PWAs, PWARCs, seropositives and their families have evolved in most areas of the state with sizable AIDS/ARC caseloads. Many of these services rely on volunteers and, in the larger counties, are stretched very thin. In more rural areas, significant population-specific service gaps remain. Throughout the state, selected service components of a comprehensive AIDS/ARC service network are completely lacking. Responding to these unmet needs requires the creation of new service components and expansion of others. Resource requirements, in the aggregate, could be considerable.

It is important here to reiterate that estimations of unmet needs and resource requirements are based on information from several knowledgeable sources and reflect relative, not absolute, judgments. Each service described in this and the previous chapter plays a key role in a comprehensive network of physical and psycho-social services to address the many and varied needs of seropositives and persons with ARC or AIDS. Models of service organization and delivery currently in place in selected counties as well as a discussion of approaches to AIDS/ARC service organization and planning are presented in the following chapters.

## CHAPTER FIVE

### ORGANIZATIONAL ISSUES RELATED TO SUPPORTIVE SERVICES

As the URSA Institute study team examined modes of service provision to PWAs/PWARCs around the state, there began to emerge certain issues which were not related to direct client services. These issues concerned organizations--the structures through which service needs are identified and services are offered. Although services may be conceptually separate from the organizations that provide them, in practice, without sound structure, needed services will not be delivered. And if they are delivered, they may not be delivered well without sound organizational support. There is cause for concern about the stability and strength of the organizations providing supportive services to California's PWAs/PWARCs. This chapter describes the needs of these agencies. Recommendations for organizational remedies are found in Chapter Seven.

Many, if not most, of the supportive services described in the preceding chapters are provided by nonprofit organizations in California. This situation is consistent with the important role that nonprofit agencies play in the provision of other human services, in California and across the nation. These nonprofit organizations may be under contract to a county or state agency to deliver services or they may also be operating on their own initiative using their own funds to serve PWAs/PWARCs. In either case, community-based agencies are acting to meet the needs of PWAs/PWARCs for services that allow them to function with maximum independence in the community. In almost all of the counties visited for this project, a community-based agency has emerged as the focal point of supportive service provision. These focal agencies are referred to in this report as "AIDS service agencies."

An AIDS service network refers to the group of related services provided by public and private agencies (described in detail in Chapters Three and Four) which have been used by PWAs/PWARCs in many communities. In some cases these organizations are existing providers of human services able to include PWAs/PWARCs in their caseloads. Examples of these are home health agencies, substance abuse treatment providers and hospice organizations. In many cases, these agencies, particularly the AIDS service agencies whose clients are primarily PWAs/PWARCs, were created in response to the AIDS

crisis. The recently created organizations carry the bulk of the burden in meeting supportive service needs. It is in these entities that the most imposing organizational challenges lie.

## **LACK OF INFRASTRUCTURE AND ORGANIZATIONAL CAPABILITIES**

In the course of conducting the site visits to six locations around the state the URSA Institute team observed the operations of several AIDS service agencies. In addition to our own observations, we spoke with executive directors, staff and clients. While not conducting a formal organizational diagnosis in each site, we did observe a consistent set of problems or issues arising at most of the agencies visited. These issues did not concern services directly but related to the organizational capability of the agencies and the existence of mechanisms which contribute to the strength and stability of human service agencies. On the basis of these observations, there appear to be seven functional areas where AIDS service organizations have weaknesses which may impede their ability to continue serving PWAs/PWARCs. It must be understood that not all the agencies visited operate with these problems. Most of the agencies visited currently provide high quality care despite these organizational limitations. The functional areas requiring assistance are:

- **strategic planning**--deciding on organizational goals and objectives based on an analysis of the environment and an articulation of values. This includes assessing the need for services and incorporating that understanding into a strategic plan. Given the rapidly growing caseload of PWAs/PWARCs and the changing demographic characteristics of the infected population, this is an especially critical function for an AIDS service agency;
- **program planning**--once the overall strategy has been defined, allocating resources within the organization to fulfill the agency's mission. With the scarcity of resources for supportive services, this function must insure that existing resources (including volunteers) are used efficiently;
- **Board recruitment and development**--with many AIDS service agencies having begun as informal associations of gay-identified individuals, the formalization of governance structures, the training of Board members in their responsibilities and recruitment of Board members from the broader community have been

difficult for some. Without a strong Board, a community-based agency's likelihood of success is reduced;

- **fund development**--contributions are a significant source of income for community human service agencies. Since many of the most basic functions performed by an AIDS service agency (emotional and practical support, advocacy, case management) are not easily funded under existing public programs, finding ways to support an agency's operations is critical. In San Francisco and Los Angeles, AIDS service organizations have developed sophisticated fund raising abilities. The fund development observed outside the major urban areas of the state relies on special events and individual contributions rather than more formal efforts to find larger and more stable sources of support;
- **financial management**--the flow of money through an organization keeps the agency alive and enables the agency to provide needed services. Among the AIDS service agencies visited, particularly the smaller ones, there was a need for improved bookkeeping practices;
- **personnel management**--job descriptions, personnel procedures, supervision and staff development capabilities should be strengthened. As the epidemic spreads, it will be essential for AIDS service agencies to have personnel systems capable of supporting larger staffs. For direct care workers (paid or volunteer) the stress of working with PWAs/PWARCs is high; it should not be exacerbated by the stress of working in a poorly managed setting;
- **volunteer management**--volunteers are the heart of the supportive services used by PWAs/PWARCs around California. They help in ways that paid staff does not and they do it out of feelings of love and personal commitment. In many AIDS service agencies, without volunteers there would be no services. Better methods for volunteer recruitment, training, retention and supervision are needed. As the need for supportive services increases, the simple impulse to help will no longer be sufficient. That impulse must be organized so that volunteer resources are used judiciously and PWAs/PWARCs receive the best possible care. A closer examination of the role of volunteers in the AIDS service agency is provided in the following section.

For any community-based organization, these organizational concerns, if not addressed and remedied, can interfere with its mission to service its clients. In the current public policy context surrounding AIDS/ARC, the voluntary agency and the volunteers themselves are likely to continue to be the predominant providers of service. Given the informal origins of many AIDS service agencies, the enormous pressure (even in smaller counties) of responding to very intense service needs and the lack of "hard" funding for these services, it is critical that these building blocks of organizational success be in place.

### **THE ROLE OF VOLUNTEERS IN AN AIDS SERVICE NETWORK**

Without volunteers, many of the most basic supportive services for PWAs/PWARCs (e.g. emotional and practical support, advocacy and information and referral) would be virtually impossible to provide. Some of these basic or core services are provided by paid staff in AIDS service agencies. However, since there are no regular funding sources for these services, it is difficult for the agencies to hire at a staffing level adequate to meet the demand. PWAs/PWARCs must rely on agencies to find, train and manage people who provide direct care. Providing this kind of direct, personal care to PWAs/PWARCs is intense and stressful work. The URSA Institute believes that the growing caseloads and the heavy reliance on volunteers to provide care, when combined with the demanding nature of that work, have produced a situation that is untenable in the long-term. It is unreasonable to assume that there will be a continual supply of volunteers to serve PWAs/PWARCs in California.

Voluntarism is an important and valued part of the human service enterprise throughout the United States. In general, Americans have given freely of their time and effort to help those in need. The volunteer response to the AIDS/ARC epidemic in California has been extraordinary, not just among the groups where the disease has struck the hardest, but also among the general population. Individuals from a wide range of cultures, ages, professions and political and socio-economic backgrounds have given thousands of hours of their time to relieve the suffering of PWAs/PWARCs. Given the limitations of the study, we were not able to produce detailed estimates of the number of volunteers and volunteer hours devoted to caring for PWAs/PWARCs. However, during the site visits conducted for this study, we identified examples of the critical role played by volunteers in AIDS service agencies.

- In Los Angeles, the Shanti Foundation reported that its 196 volunteers provided over 50,000 hours of counseling to 550 clients in 1986. The AIDS Project of Los Angeles indicated that its "buddy" program involves approximately 225 volunteers who give 15 hours of support per week, producing an annual total of almost 170,000 volunteer hours.
- In San Francisco, the Shanti Project organized over 130,000 hours of volunteer time for the care of PWAs/PWARCs in 1986.
- In Sacramento, the 150 practical and emotional support volunteers affiliated with the Sacramento AIDS Foundation Hand-to-Hand program currently provide approximately 2000 hours per month to the agency's clients. This represents a 100% increase in volunteer time over the previous year. Funding limitations, however, do not provide for a paid volunteer coordinator. The SAF serves approximately 75 active AIDS/ARC cases.
- In Fresno, volunteers with the Central Valley AIDS Team (CVAT) provided 3174 hours of practical and emotional support for seropositives, and PWAs/PWARCs during 1986. During that time they cared for about 40 PWAs/PWARCs. In addition, the volunteer coordinator, herself a volunteer, contributed over 1300 hours of supervision/coordination time in 1986. Recent communication with the CVAT indicates that the levels of volunteer time used will be significantly greater in 1987.
- In San Jose, volunteers with the ARIS Project provided a total of 2722 hours of one-to-one emotional support for PWAs/PWARCs in the nine-month period ending May 1987. Additionally, practical support volunteers provided 3085 miles of transportation over 324 hours, as well as 220 hours of homemaker assistance to ARIS' clients during a recent six month period. ARIS currently has an active volunteer base of 99 individuals and a caseload of approximately 50 clients.

This remarkable outpouring of help has eased the pain, loneliness and despair of infected people.

Several of the staff at the AIDS service agencies visited reported that it was becoming increasingly difficult to find volunteers to care for PWAs/PWARCs. In addition, the volunteers require a high level of support themselves. In Los Angeles, the

Shanti Project indicated that its volunteers were increasingly reporting a need professional counseling as a result of their care-giving activities. Because there is no funding for volunteer coordination in many sites around the state, often the volunteers are not adequately supervised. This adds to the frustration that the volunteers experience. For a growing number of unpaid caregivers, the stress of helping PWAs/PWARCs is too intense to be relieved entirely by volunteer support groups. This experience was echoed by other providers across the state. Many volunteers pay a high price for their willingness to give.

As our knowledge and sophistication about how to provide long-term care for PWAs/PWARCs grows, the role of volunteers is likely to change. While volunteers will continue to perform an essential function in a community's AIDS service network, other sources of help must be developed and used. Practical support, case management and advocacy should be performed primarily by paid staff. The efforts of volunteers can support these functions and volunteers can continue to serve in other important ways, such as providing transportation. The on-going support of terminally ill people with few other sources of comfort cannot be so undervalued in this society as to rely so heavily on the charitable instincts of our citizens. Public monies for this purpose must be found and made available if California is to maintain its national leadership in the humane care of PWAs/PWARCs.

## **PERCEPTIONS OF THE CAPABILITY OF HUMAN SERVICE SUBSECTORS**

In an effort to assess the perceived capabilities of the state's public and private human service resources, our survey of providers in 20 counties asked the respondents to rank each of eight human service subsectors (public and private social services, health care, mental health services and substance abuse treatment) in terms of "their overall abilities to meet the supportive service needs of PWAs/PWARCs" in their counties. The possible rankings ranged from "very capable" to "incapable." The analysis of those responses is shown in Tables 5.1-5.4. The "capability rating" is a weighted average of the aggregate distribution of the responses. Under this system, the maximum possible capability rating is 200, the minimum 0.



**Table 5.1. Capability Ratings of Human Service Providers.  
All Counties**

<u>Human Service Subsector</u>	<u>Capability Rating</u>
Public Health Care	93.1
Public Substance Abuse Treatment	75.0
Public Social Services	74.5
Private Health Care	62.9
Private Social Services	61.5
Public Mental Health Services	60.4
Private Substance Abuse Treatment	57.8
Private Mental Health Services	53.7

Among the California service providers surveyed, public sector agencies are seen as generally more capable than private agencies in their abilities to meet the needs of PWAs/PWARCs. Table 5.1 shows that across all respondents to the survey, the public health care subsector is perceived to be the most capable provider of supportive services to PWAs/PWARCs. This is followed by public substance abuse treatment and social service programs. Private health care and social services are grouped closely together in terms of overall capability rating. The mental health care subsector is seen as less capable, with only a moderate difference in rating according to public or private auspice. When perceived subsector capabilities are further analyzed by county size, some differences with important implications for service planning emerge.

**Table 5.2. Capability Ratings of Human Service Providers.  
Large Counties**

<u>Human Service Subsector</u>	<u>Capability Rating</u>
Private Mental Health Services	88.9
Public Social Services	77.8
Private Health Care	77.8
Public Health Care	77.8
Private Social Services	77.8
Public Substance Abuse Treatment	75.0
Private Substance Abuse Treatment	75.0
Public Mental Health Services	44.4

The capability perceptions of respondents from counties with populations over 500,000 are shown in Table 5.2. In California, these are the counties with the most experience in dealing with the community care concerns of PWAs/PWARCs. The private mental health agencies and providers were rated as the subsector most capable of responding to the supportive service needs of PWAs/PWARCs. In marked contrast to the overall sample, six of the eight subsectors are ranked very close together in overall capability. This seems to indicate that providers in the AIDS service network have roughly similar expectations from this widely differing group of agencies. Of particular interest is that there is no difference in the rankings between public and private health care agencies and between public and private substance abuse treatment providers. In general, there is no sharp division between public and private providers in the largest counties. The subsector viewed by this group of counties as least capable of meeting the needs of PWAs/PWARCs is public mental health.

**Table 5.3. Capability Ratings of Human Service Providers.  
Medium-sized Counties**

<u>Human Service Subsector</u>	<u>Capability Rating</u>
Public Health Care	88.9
Public Substance Abuse Treatment	77.8
Public Social Services	66.7
Private Health Care	59.3
Private Social Services	57.6
Private Substance Abuse Treatment	50.0
Public Mental Health Services	37.0
Private Mental Health Services	37.0

Among the counties with populations between 100,000 and 500,000, the public health care subsector clearly has the highest level of perceived capability for meeting PWAs/PWARCs service needs, according to our survey respondents. In general, public agencies are rated as more capable than private providers as shown in Table 5.3. Surprisingly, public and private mental health service providers are viewed as being the subsector with the least capability for responding to PWAs/PWARCs supportive service needs. Mental health is the lowest ranked public subsector by the respondents from the medium-sized counties. While private mental health agencies are rated the most capable

by the large counties, among the providers in medium-sized counties they are at the bottom of the distribution.

**Table 5.4. Capability Ratings of Human Service Providers.  
Small Counties**

<u>Human Service Subsector</u>	<u>Capability Rating</u>
Public Health Care	128.7
Public Social Services	100.0
Private Mental Health Services	80.0
Private Substance Abuse Treatment	75.0
Public Substance Abuse Treatment	60.0
Private Health Care	62.9
Public Mental Health Services	57.1
Private Social Services	50.0

Respondents from the smallest counties (fewer than 100,000 residents) have the greatest faith in the mainstays of the public human service system--public health care and social services. As Table 5.4 reveals, both of these subsectors receive very high ratings for their perceived capabilities. In many smaller counties throughout the state, there are very few private resources that can be applied to maintaining the maximum independence of PWAs/PWARCs. Assuming that explanation has some validity, then it is interesting that private mental health services are ranked higher than those same services provided by a public entity. This seems to reflect a pervasive feeling regardless of county size that the public mental health subsector, under current circumstances, will not be able to play a major role in responding to the supportive services needs of the PWAs/PWARCs population.

Based on the perceptions reported here, public agencies are likely to continue to play a major role in serving PWAs/PWARCs, especially health care and social services. Unless private providers take a more active and visible role, public agencies will continue to be viewed as the expected source of help for PWAs/PWARCs by most providers of health and social services around the state. This is especially true among the smaller counties in California. A significant exception to this generalization is public mental health. The data show very little faith on the part of human service providers across the state in the public mental health system. This finding is consistent with the interview

data which found mental health services for PWAs/PWARCs almost impossible to obtain. When they are used, it is rare that they come from public agencies.

These survey findings are anomalous given that many of the supportive services identified in the site visits were being provided by community-based nonprofit agencies. Other than serving as a vehicle for IHSS and some income assistance programs, the public social service subsector actually has a limited function in the present AIDS service system. The role that the nonprofit sector plays in a community's AIDS service network is not well understood by all the participants in that network. This lack of understanding inhibits the development of coordinated AIDS service networks and makes it more difficult for nonprofit providers to obtain support for their work. A more formal designation of the AIDS service agency in each community affected by the disease would help to clarify the role of the nonprofit and public sector service providers. Such designation could occur under a state-sponsored effort to create the planning and service delivery coordination required to bring together an AIDS service network. Given the major role that voluntary agencies play in supporting PWAs/PWARCs, there should be better recognition of that contribution. Formal service delivery models which incorporate nonprofit agencies are described in the following chapter.

## **CHAPTER SIX**

### **AIDS SERVICE NETWORK MODELS: ACTUAL AND RECOMMENDED**

#### **INTRODUCTION**

An explicit objective of this project was the analysis and development of supportive service delivery models. As used here, the term model refers to a structure and set of relationships among the providers in the AIDS service network. The types of services provided to PWAs/PWARCs and the organizations providing them are described in detail in Chapters Three and Four. In this chapter we turn our attention to how those individual agencies relate to one another. This analysis begins with a description of the factors that influence service delivery models, then moves on to portraits of the principal AIDS/ARC service delivery models now operating in California. This chapter concludes with the URSA Institute's recommendation for a new model of service delivery to PWAs/PWARCs.

#### **FACTORS AFFECTING THE DEVELOPMENT OF SERVICE DELIVERY MODELS**

Before discussing the specific models of service delivery and organization which the URSA Institute identified in its analysis of supportive services for PWAs/PWARCs in California, it is important to describe the specific factors which shape the development of service organizations. These are forces which affect the structure and functioning of a service delivery model. They determine, in part, the number and type of agencies in an AIDS service network, the relationships among those agencies, which agencies have lead positions in the network, and the ability of the network to change over time.

The resource limitations of the study did not allow us to perform a quantitative analysis of service systems. We are therefore unable to assess the relative effects of each of the following factors on the development and functioning of system of supportive services to PWAs/PWARCs. Our information is anecdotal and qualitative. The analysis contained here, however, is based on extensive interviews with the participants in six widely different AIDS service networks around the state. Added to that interview

information is the study team's mapping of services based on the data provided by the PWA/PWARC group interviews.

With those considerations explicitly identified, several factors appear to contribute to the development of supportive service models for PWAs/PWARCs found in California. It must be understood that any local planning efforts associated with creating or strengthening an AIDS service network must take these factors into consideration. They represent constraints and opportunities that are as real as the supportive service needs described in preceding chapters.

The first of these factors is **local financial resources**. The availability of funds for services from all sources is one of the most important factors influencing the development of AIDS/ARC service systems. Outside of Medi-Cal and In-Home Supportive Services, there has been very little public money involved in providing supportive services to persons with AIDS or ARC. In some instances, county governments have been able to finance limited services. In other cases, private funds from individuals, groups and foundations have been used. Where such funds are lacking, or difficult to obtain, it has severely retarded the growth of a comprehensive service system for PWAs/PWARCs.

Another important factor is **local organizational resources**. Existing supportive service organizations often form the basis from which an AIDS service network can grow. Communities which have a well developed human service system are in a better position to create a network than those in which there is a weak system of services. Likewise, the existence of a strong voluntary tradition of informal service giving makes possible the creation of an AIDS service agency which depends heavily on volunteers. Although the availability of strong organizational resources is partly a function of funding, we found instances of communities where there was not a strong tradition of formal funding for human services but, because informal helping was an accepted part of community life, it was possible to create a basic AIDS service network.

In addition to community traditions of organized helping, the political strength and cohesion of the communities from which the infected population comes also affects how service arrangements develop. Most of the individuals diagnosed with AIDS or ARC in California have been gay or bisexual men. Communities with visible and well established gay political and service organizations have been most successful in creating an AIDS service network. Where the gay community has already established its credibility and its

competence with local policy-makers, it has been easier to develop a service system which has gay men as its primary clients.

**Geographic factors**, the concentration or dispersion of the infected population over a specific area, also influence how a system develops and what shape it takes. Communities which have a highly concentrated population of PWAs/PWARCs can more easily centralize certain heavily used services, such as emotional support. This situation encourages the development of a one or more relatively large agencies which serve as focal points for an AIDS service network. In communities where the infected population is not concentrated but in fact is widely distributed within a geographic area, services are generally more fragmented and difficult to coordinate.

**Differences in caseload size** also help to shape service delivery models. Regardless of the geographic distribution of PWAs/PWARCs in a community, a "critical mass" of clients is needed to make a formal AIDS service network (or even an AIDS service agency) an efficient use of scarce human service resources. If there is not a sufficient volume of cases, supportive services are generally provided on a case-by-case basis using existing agencies. URSA Institute recommendations on the caseload sizes appropriate to justify an AIDS service network can be found in the last section of this chapter.

Even when these factors are taken into account, the supportive service models described below may not be completely replicable. The local forces which shaped their development may be responsible for unique arrangements. Despite these limitations, there are some basic lessons that can be applied to local AIDS service network planning, even if replication of all aspects of the models is not possible.

## **EXISTING MODELS**

The site visits conducted in six California counties provided detailed information on the number and type of organizations delivering services to PWAs/PWARCs in those locations. These models are not necessarily offered as a prototype for other communities interested in creating AIDS service systems. They represent what currently exists, based on an analysis of service networks in a sample of California counties.



## Model A

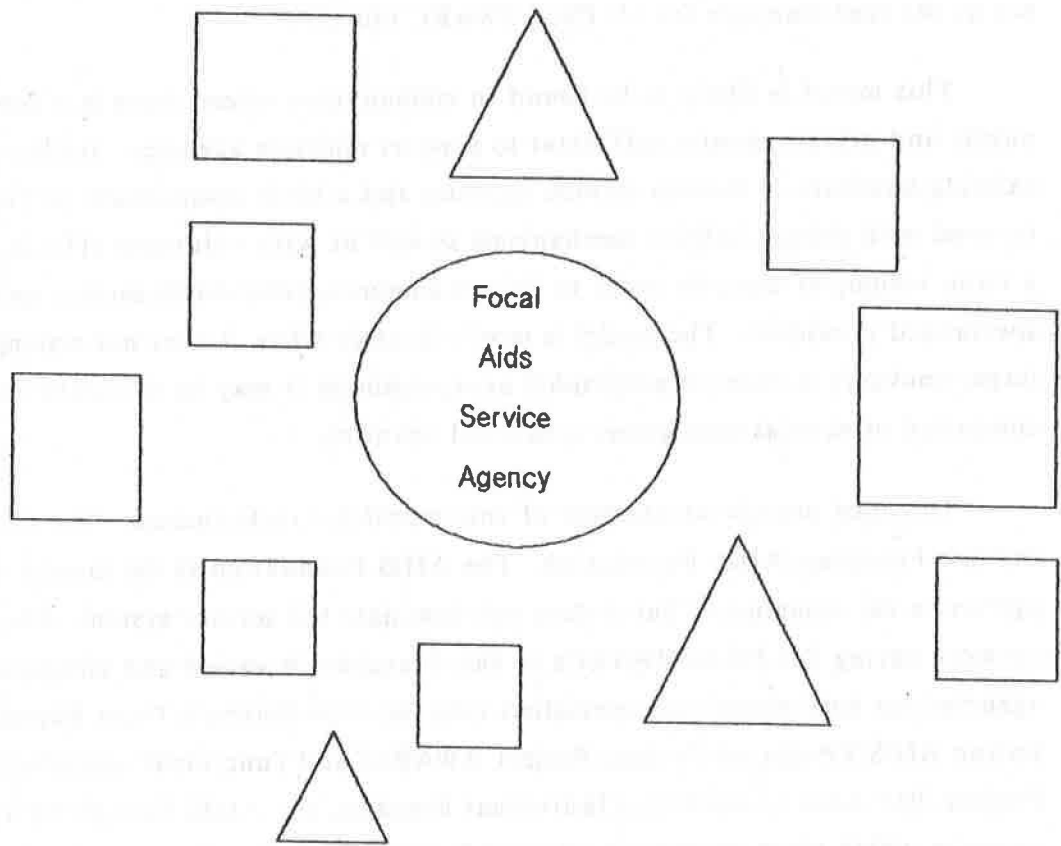
In this arrangement there is a single AIDS service agency acting as focal point for service delivery. This agency provides multiple services, typically a combination of physical and psycho-social services to most of the PWAs/PWARCs in a community. The most commonly provided services are emotional support, practical support (transportation, homemaker/chore), emergency cash assistance, case management/advocacy and information and referral. The agency is typically the most widely known AIDS service agency in the community among the general population. In addition to direct services, it generally acts as the community's primary source of information and education about AIDS and ARC. The agency has strong relations with the acute health care providers in the community.

Under this model, the AIDS service agency does not dominate the local AIDS service network, although it does play a major role in shaping the human service response to the epidemic. There is a constellation of other agencies operating in the community. Some of these agencies provide specialized services requiring expert knowledge and experience to PWAs/PWARCs who need them. We refer to these agencies as "functional specialists." In addition, there are agencies which provide a limited range of general services to sub-populations of infected individuals who may not be served by the focal AIDS service agency. These agencies are "population specialists." The site visits revealed that there are agencies which specialize in serving minority, IV drug using and women PWAs/PWARCs.

We have not identified any examples of this model where the focal agency is a department of local government. County departments, particularly the health and, to a lesser extent social services departments, are certainly important members in the Model A AIDS service network. However, the limitations in the kinds of activities that county agencies may undertake effectively preclude them from acting as the focal point of the network. Our analysis shows that the role of the AIDS service agency is invariably played by a community-based nonprofit agency. Only nonprofits may make emergency cash grants without formal eligibility determination; only nonprofits can forcefully advocate for needed services; and only nonprofits can recruit and place a large volunteer corps.

A graphic representation of Model A is shown in Figure 6.1. Note that the focal AIDS service agency is at the center of the network but does not dominate it. Most of the peripheral agencies are linked through the focal agency but it is not unusual for some

Figure 6.1. Model A Prototype



□ = Functional Specialist  
△ = Population Specialist

peripheral agencies to have links among themselves that are independent of the focal agency. The actions of the peripheral agencies do not depend on the focal agency. The pattern of relationships in the Model A network makes case management and coordination a critical function but a difficult one at times. While communication among agencies is generally good, there is no single agency capable of acting for PWAs/PWARCs across the service system. There can be (and often is) case management within the focal agency but it is unusual for there to be agreement among the providers that a single agency should act as the case manager for all PWA/PWARC clients.

This model is likely to be found in communities where there is a supply of local public and private monies sufficient to support multiple agencies. It also requires an existing structure of human service agencies and a civic commitment to respond to people in need with formal helping mechanisms as well as with volunteer efforts. There must be a large volume of cases in order to have a comprehensive AIDS service network of specialized providers. The model is most effective when it does not attempt to cover a large, unevenly populated geographic area, although it may be effective in a region comprised of several contiguous urbanized counties.

The most prominent example of this model is San Francisco. The focal agency is the San Francisco AIDS Foundation. The AIDS Foundation is the largest AIDS service agency in the community but it does not dominate the service system. The AIDS service network caring for PWAs/PWARCs in San Francisco is varied and complex. Peripheral agencies are both population specialists (the Bayview-Hunter's Point Foundation, the Latino AIDS Education Project, Project AWARE) and functional specialists (the Shanti Project, Bay Area Lawyers for Individual Freedom, the AIDS Emergency Fund). The agencies which serve special populations have expanded as the number of diagnosed cases of AIDS/ARC outside the gay, white population has increased. Similar structures can be found in Fresno, where the Central Valley AIDS Team is the focal agency and in Sacramento, where the Sacramento AIDS Foundation is at the center of a network of supportive services for PWAs/PWARCs.

#### **Model B**

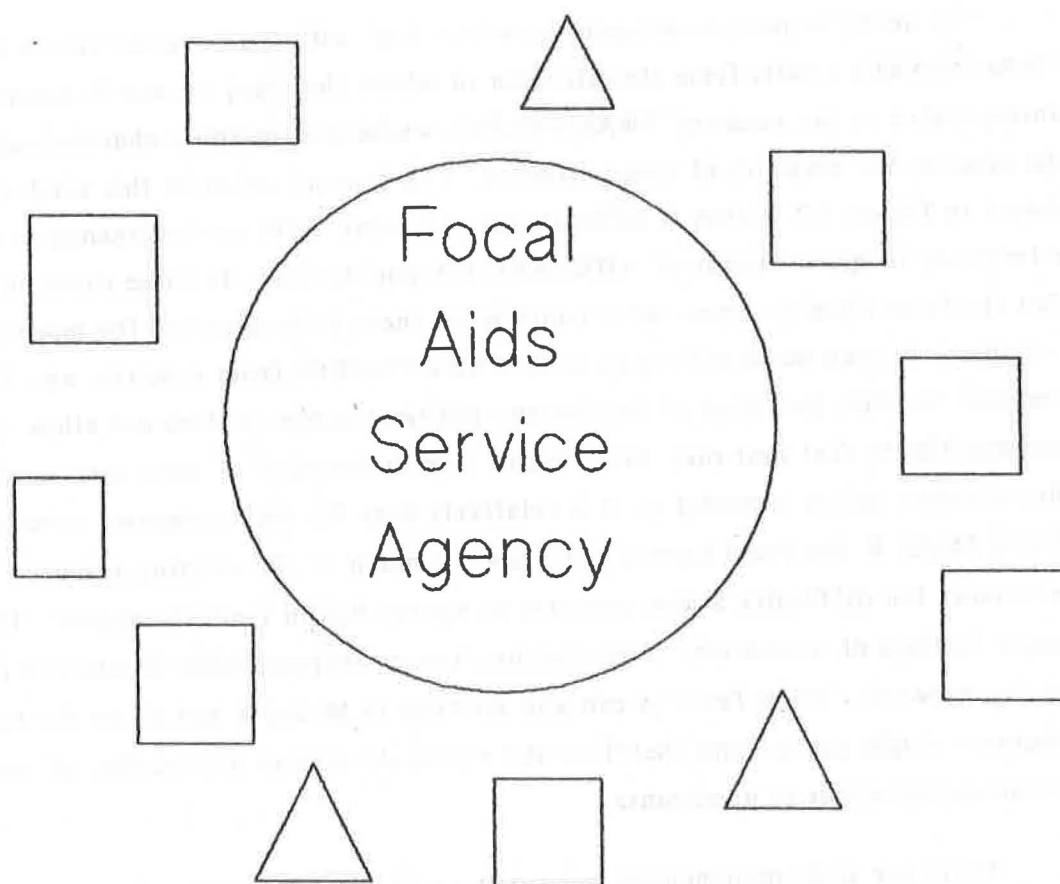
This model also assumes that there is a focal AIDS service agency, as in Model A. Its role is very similar to that of the focal agency in the previous model. Unlike Model A, however, this agency dominates the AIDS service network. There are fewer peripheral

providers. Those that do exist are more likely to be population specialists rather than functional specialists. The focal agency provides a wider range of services than found in Model A, reducing the need for separate agencies offering specialized services. More of the total network's resources are centralized in a single organizational location than in Model A. As with the previous model, there are no examples of a public organization serving as the focal AIDS service agency.

The need for peripheral agencies which deal with special populations of PWAs/PWARCs results from the situation in which the focal agency is perceived as being unresponsive to the needs of PWAs/PWARCs whose demographic characteristics are not the same as the majority of those infected. The centralization in this kind of network, shown in Figure 6.2, makes it difficult for the focal AIDS service agency to respond effectively to special needs of AIDS/ARC sub-populations. In these cases, it is sufficient that the focal agency appear unresponsive for there to be pressure for more specialized providers. It may make efforts to serve PWAs/PWARCs from minority and IV drug using communities but, by virtue of its size and political power, it does not allow these communities to feel that they have "input" into or "control" of their own services. When this situation arises in model A, it is relatively easy for new programs to be created. Under Model B, the focal agency has absorbed much of the existing resource base, increasing the difficulty a new program or agency has in finding support. This can create feelings of alienation in the communities of infected individuals and in the AIDS service network. These feelings can and do exist in Model A but given the lack of a dominant single agency and therefore the relatively greater availability of resources, they are somewhat easier to ameliorate.

There are some management advantages and disadvantages inherent in this approach. This model may be somewhat less expensive to operate as a total system than Model A. Having fewer organizations, the total proportion of funds spent on administration should be less than in the previous model. Case management is much easier since so many of the key supportive services are provided under one organizational roof. However, this approach to organizing services is less flexible. Being dominant in the AIDS service network, the focal agency may have created management structures which impede its ability to act quickly in every situation. In creating the structure necessary to support a high level of specialized activities, the focal agency runs the risk of putting some of amount of distance between itself and its clients.

Figure 6.2. Model B Prototype



□ = Functional Specialist.

△ = Population Specialist

Los Angeles County (excluding Long Beach) provides the clearest example of this model in California. The AIDS Project of Los Angeles is the focal AIDS service agency. Unlike San Francisco, there are few other agencies with functional specializations. Aid for AIDS, which makes cash grants, and the the Shanti Foundation were the only major agencies we could identify providing specialized supportive services to PWAs/PWARCs. To a limited extent, APLA provides certain services which overlap with those of Shanti. The other peripheral agencies had more of a special population focus: the Minority AIDS Project of Los Angeles, the Women's AIDS Project and El Centro Human Services Corporation. (The Watts Health Foundation is also a participant in the effort to serve PWAs/PWARCs but had not begun its program at the time of our visit.) This characteristic, a relatively high number of population specialists, is an important indicator of a Model B system.

A prerequisite for a Model B system is that the focal agency must have excellent referral relationships with local hospitals. One consistent finding across sites visited for this project is that almost all PWAs/PWARCs enter the supportive service network through the acute health care system rather than by way of other community-based agencies. Without strong connections to hospital discharge decisions, the focal AIDS service agency could not maintain the caseload size required for dominance in the network. Within a very large caseload, there is likely to be a sufficient subgroup of PWAs/PWARCs requiring specialized support, such as emergency housing, employment counseling and transportation. In creating these specialized services, the focal agency reduces the need for other agencies to provide them.

The other requirements of this model are that at least a moderate amount of resources be available for supportive services for PWAs/PWARCs. Although the gay community in Los Angeles is visible and politically aware, it has not been able to organize the same type of service response as in San Francisco. As a result, there is less local funding (public and private) for the PWA/PWARC supportive services network. In Los Angeles, a concentration of AIDS/ARC in a well defined geographic area has made it possible for Model B to develop in its current form.

### Model C

The last model of service organization is different from the first two in one important respect; there is no focal agency. In communities where Model C has been

identified, there is an AIDS service agency providing a set of core services but it does not serve as a common point of entry into the network for PWAs/PWARCs nor does it provide an inter-agency case management function. This system is much more loosely organized than the first two. The relationships between providers in the network are more informal. Figure 6.3 illustrates this arrangement.

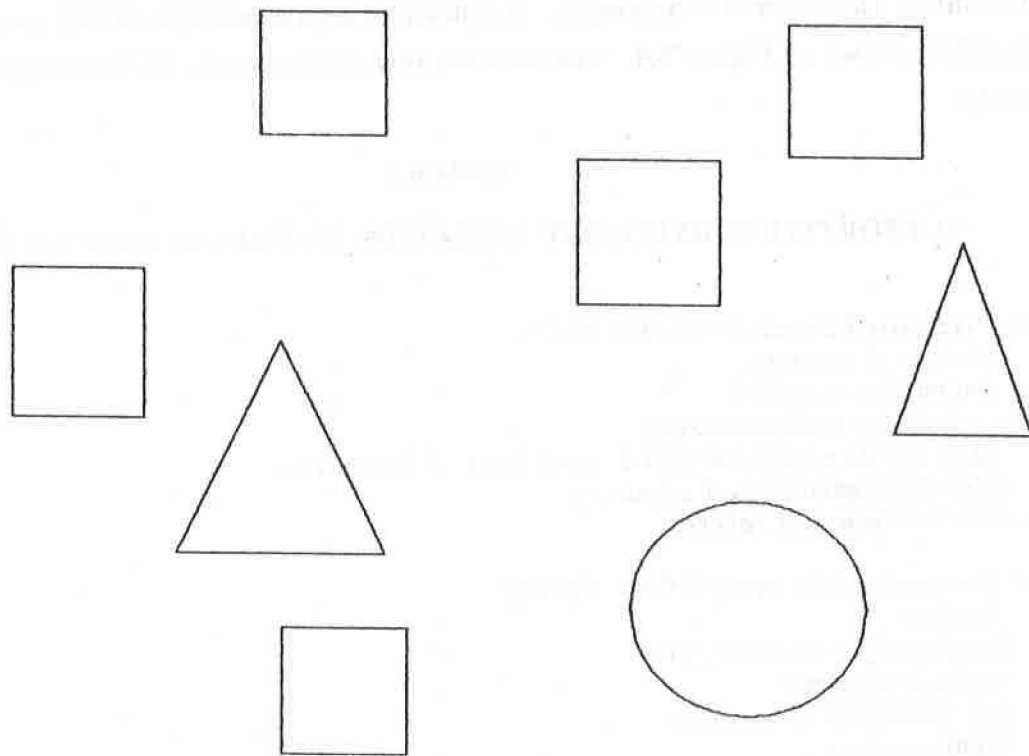
Under this model, it is possible for the same services found in Models A and B to exist. Model C can be just as comprehensive as the other models, although fewer of the participating agencies are devoted to serving PWAs/PWARCs exclusively. A significant difference is that the burden of integrating services to form a "package" is placed more heavily on the individual client. If PWAs/PWARCs are physically and mentally capable of acting as their own case managers there is no disadvantage being served under a Model C service arrangement. Since most PWAs/PWARCs experience a loss of functional ability at various points during their illness, however, there is a strong possibility that they will receive somewhat less comprehensive care than would be likely under Models A or B.

Model C is likely to be found in communities where there are relatively fewer resources. It reflects a community where the infected population has little political power. The AIDS service agency, typically gay-identified, has not established itself as a credible lead agency in the community. The core services (emotional and practical support, cash and basic assistance, case management/advocacy and information and referral) are decentralized in a number of small agencies rather than centralized in a focal AIDS service agency. It is the least expensive of the three models since it involves more agencies whose supportive service focus goes beyond PWAs/PWARCs. Since there are relatively fewer agencies which specialize in caring for PWAs/PWARCs and more agencies which include PWAs/PWARCs as one client group among a larger pool of clients, fewer new administrative and service dollars are needed to operate the network.

Public agencies are likely to play a stronger role under this arrangement than they do in the two previous models. Without a community focus in the network, the public health and social service departments are more important in setting the priorities and influencing the structure of the network. Santa Clara County and, to a lesser extent, Riverside County, exemplify this model.



Figure 6.3. Model C Prototype



○ = AIDS Service Agency

□ = Functional Specialist

△ = Population Specialist

## A NEW APPROACH TO SUPPORTIVE SERVICES FOR PERSONS WITH AIDS/ARC

Based on our analysis of the advantages and disadvantages of existing service arrangements, the URSA Institute has developed a new approach to organizing supportive services for PWAs/PWARCs. This approach gives county-level service planners a framework for developing their own service systems. It integrates elements from all three models into a three-tiered framework. A schematic representation of the recommended approach is shown in Figure 6.4. The services included in each tier are displayed in Table 6.1.

Table 6.1

### SUPPORTIVE SERVICE ORGANIZATION BY PREVALENCE OF NEED

#### Level I (required by all PWAs/PWARCs)

- emotional support
- companion services
- emergency cash assistance
- basic needs assistance (food, clothing and furniture)
- case management and advocacy
- information and referral

#### Level II (required by many PWAs/PWARCs)

- housing
- intermediate nursing care
- hospice services
- psychological counseling
- legal services
- home health services
- emotional help for loved ones
- nutrition

#### Level III (required by some PWAs/PWARCs)

- adult day (health) care
- drug and alcohol treatment services
- child-oriented services
- respite services
- skilled nursing care
- special services for women

#### Level I

This model assumes that all PWAs/PWARCs require a core set of supportive services. These are referred to as Level I services. Currently in California, volunteers play a major

Figure 6.4. Recommended Service Network Organization



role in the provision of many of these services. Not all of those who need these services actually use them; there are sometimes psychological, cultural and practical barriers to service use which prevent PWAs/PWARCs from entering the system. Given that Level I services are essential to all PWAs/PWARCs, it is imperative that they be provided in ways that respect the language, cultural and ethnic diversity of the infected population. Although this consideration is important at each level, it is particularly critical at Level I to assure full access to core services. Level I services are most effectively provided by a nonprofit AIDS service agency.

It is our recommendation that every community with an active AIDS caseload of more than fifteen should have a single designated AIDS service agency offering Level I services. Fifteen diagnosed AIDS cases was chosen as the minimum number based on several assumptions. First, it is assumed that for every diagnosed case of AIDS there are approximately ten cases of ARC in a given population. Fifteen AIDS cases then translates into 165 AIDS/ARC cases. Interviews with service providers and infected individuals across the state suggest that approximately half of PWAs will be users of supportive services at any given time. The expected service use rate among PWARCs is somewhat less, approximately one-third. Applying these use rates to an AIDS/ARC caseload of 165 results in a supportive services caseload of 50-60 clients. This is a sufficient client base to justify the creation and support of an AIDS service agency providing all Level I services.

## Level II

The need for the services included under Level II is less universal than Level I. These services are needed by many (up to 75% at any one time) but not all PWAs/PWARCs. Level II services are more specialized than Level I, often requiring a higher degree of professional training and a higher commitment of capital resources. In smaller communities, these services should be provided by existing human service organizations, such as hospice agencies, home health agencies and intermediate care nursing facilities. In large communities where the AIDS caseload exceeds 500, it is reasonable to see agencies which are functional specialists providing many of these services. For most of these services, the need for knowledge of the particular requirements of PWAs/PWARCs strongly suggests that a moderate degree of AIDS/ARC expertise would be beneficial. If there are no specialized agencies, then existing agencies should have specialized programs or staffs for Level II services.

### Level III

Only some (generally not more than 25% at one time) PWAs/PWARCs require the services listed under Level III. Some Level III services are actually entire service systems. Alcohol and drug treatment programs and child welfare services exist in independent service networks. To be used effectively in the AIDS service network model, these systems must be formally involved with AIDS service agencies. Written agreements are a useful starting point for this involvement. These services are generally even more specialized than those included under Level II. Only the largest communities in the state can afford to have providers in these areas who specialize in caring for PWAs/PWARCs. Adult day programs (with a health or social service orientation), respite care and skilled nursing care can all be provided by existing agencies where the AIDS caseload is less than 500.

In using this model for planning services, we recommend that a community concentrate first on Level I services. These must be in place before the AIDS service network can start to function. In most cases, a community-based nonprofit agency is the most appropriate provider of these services. A minimum of 15 diagnosed AIDS cases is sufficient to justify the creation of such an agency. Once those services have been established, local planners should begin to identify where in the system of existing providers Level II services can be found. Efforts should be made to build on existing resources, if possible, rather than create new organizations. In all but the largest communities, most Level II and III services will be available from agencies which do not specialize in serving PWAs/PWARCs.

The URSA Institute's recommendation that a nonprofit agency serve as the core or focal agency does not imply that public agencies should play a secondary role. Public human service agencies have an important part to play in the supportive service system. The survey results reported in Chapter Five reiterate that. Their most important function, however, is in leading a coordinated policy-making and planning effort across the spectrum of AIDS-related issues: health care, prevention and education and supportive services. These three elements of AIDS activity must be coordinated at the county level. Only a county agency, the Health Department in most cases, can undertake such an effort effectively. With regard to planning for supportive services for PWAs/PWARCs, the county's role should be to assure that the service network is part of the broader AIDS treatment and prevention plan. The county must orchestrate the overall coordination of

public and private activity at the policy level. The focal AIDS service agency must orchestrate the supportive services system for individual clients.

The three-tiered ordering of AIDS/ARC supportive services can be applied to any of the three models of local service organization described earlier in this chapter. Selection among Models A, B or C will depend on local circumstances and abilities. The approach outlined in this section cuts across that classification to guide planners in where to start creating a service system and what service providers to include at what stage. Attention must be devoted to both dimensions of an AIDS service network (the structure of the system and the supportive services included) for public and private agencies to respond effectively and humanely to the epidemic.

## CHAPTER SEVEN

### RECOMMENDATIONS FOR SUPPORTIVE SERVICES

The preceding chapters have discussed the existing array of AIDS supportive services in a sample of communities across the state. Discussions with service providers and persons with AIDS or ARC assisted us in developing a conceptual framework of AIDS/ARC needs, both physical and psycho-social, and in understanding the support service implications of these needs. Persons with ARC or AIDS, community-based AIDS/ARC service agency staff, private health care providers, and others provided information on current levels and configurations of support services for PWAs/PWARCs in Los Angeles, San Francisco, Sacramento, Santa Clara, Fresno and Riverside counties. Their counterparts in 20 additional counties provided information on current supportive service resources and anticipated needs. From these sources, a community supportive services framework was constructed which identified a minimum set of services for each county to provide basic support to persons with AIDS or ARC. Two additional levels of supportive services to augment these were also identified. This three-tiered model represents our basic recommendation for a minimum level of supportive services for persons with AIDS or ARC.

A series of issues pertaining to matters of AIDS/ARC policy, service planning, service linkages, the needs of particular AIDS/ARC subpopulations and continuing staff education/training were also identified during the course of our inquiries. This final chapter presents a series of recommendations addressed to several audiences: state government, county government, and community-based AIDS/ARC service agencies. This series of 21 recommendations is based upon three interrelated premises. These are:

- 1) The supportive service needs of persons with ARC are, for service planning purposes, identical to those of persons diagnosed with AIDS.
- 2) The overriding purpose of providing supportive services to persons with ARC or AIDS should be to maximize physical and psycho-social independence given the particular health and functional status of the individual. Likewise, as various community-, home-, or institution-based services are needed by PWAs and



PWARCs, providing care in the least restrictive environment should be a prevailing concern.

- 3) Supportive services must be organized and delivered in a manner which balances sensitivity with efficiency, given rapidly growing AIDS/ARC caseloads and the general inadequacy of funding for supportive services statewide.

Recommendations 1 through 4 address issues of statewide AIDS policy; 5 through 11 concern statewide program matters in supportive services, and recommendations 12 through 21 are directed toward community service delivery issues.

#### **Recommendation 1:**

**State government should take the leadership in formulating policy and in expanding its fiscal commitment to AIDS/ARC supportive services.**

A coordinated statewide policy on AIDS/ARC supportive services, integrating all appropriate service agencies (health services, mental health, substance abuse, social services) should guide the development of new AIDS/ARC supportive services and the expansion of existing service networks. AIDS/ARC is a statewide public health problem creating vast needs for basic supportive services (emotional support, practical support, cash assistance, "basic" assistance, case management, information and referral) throughout the state. Current responses are uneven and seriously overburdened. The state should fund programs to provide core supportive services (see Chapter Six) to PWAs/PWARCs, seropositives and their loved ones in each county whose caseloads justify the need for these services. We recommend that the state investigate the use of a block grant model to distribute funds to each county and that individual levels of support be based upon the numbers of seropositives, persons with ARC or persons with AIDS. We further recommend that the fiscal agent in each county be the key AIDS service agency with formal letters of agreement from all agencies in the AIDS service network in the county. As a condition of funding, such agreements should clearly identify the roles to be played by each organization, corresponding to the level of funding and the client populations to be served. A single agency should assume responsibility for case management and all funded agencies should agree on a standard client intake and record-keeping system.

**Recommendation 2:**

**Expand AIDS benefits to PWARCs.**

Although a premise underlying each of these recommendations, it is important to reiterate that supportive service needs of persons with ARC are indistinguishable from those of persons with AIDS. Programs, services and benefits, both public and private, now available to PWAs should be extended uniformly to individuals diagnosed with ARC.

**Recommendation 3:**

**The state should adopt a comprehensive AIDS/ARC/seropositive anti-discrimination law.**

Cases of AIDS-related employment and housing discrimination occur throughout the state, creating additional problems and adding immeasurably to the emotional burden of the AIDS/ARC/seropositive diagnosis. A comprehensive anti-discrimination law protecting the rights of this population should be adopted to deter discrimination and to provide clear legal recourse for victims of AIDS discrimination. To make such a statute truly effective, free or low-cost legal services should be expanded to provide access to the legal system for the AIDS/ARC population.

**Recommendation 4:**

**Public benefits programs should be better coordinated at the eligibility level.**

Coordination of eligibility standards and policies regarding documentation should be standardized across programs and services should be extended equally to persons with ARC as well as PWAs. Eligibility processes should be centralized and required AIDS/ARC eligibility documentation clearly explained to applicants in advance. State and county benefits programs (MediCal, IHSS, SDI, GA) should have a single eligibility determination to avoid unnecessary time and paperwork burdens on PWA/PWARC applicants, their families or social service agency staff. Eligibility determinations should be made expeditiously and benefits should all commence shortly following the date of application.

**Recommendation 5:**

**A program of management assistance to AIDS/ARC service agencies at the community and county levels should be provided to strengthen organizational capacities.**

Assisting new and/or expanding AIDS/ARC service organizations with focused management assistance was identified as a hidden need by most service agencies contacted for this study. Such assistance should be directed toward building internal management capacities in the following areas: program planning, evaluation, needs assessments, budgeting and fiscal management, personnel management, volunteer management, board-staff relations and related issues.

**Recommendation 6:**

**Case management should be a major supportive service priority at the state and community levels.**

Delivering supportive services and health care to persons with AIDS or ARC often involves multiple agencies and service providers. Communities should develop, and the state should support, innovative and effective case management services to reduce the burden of locating and qualifying for services and benefits now assumed by PWAs/PWARCs themselves, their families and volunteers. Case management should represent the nucleus of the AIDS/ARC service network in a community and should be provided by qualified staff to ensure that the array of needs experienced by PWAs/PWARCs during the course of their illnesses are adequately and sensitively addressed.

**Recommendation 7:**

**Policies and services provided by the In-Home Supportive Services program should be changed in response to AIDS/ARC needs.**

For some clients across the state, the per-person allocation of IHSS resources is insufficient to meet the daily needs of debilitated PWAs/PWARCs and allocation policies should be reviewed and higher per-client allocations permitted. Locating qualified IHSS workers willing to work with PWAs/PWARCs can be especially burdensome to clients or their families. Each county should develop, and update regularly, a roster of IHSS

workers available for work with PWAs/PWARCs. In-home workers should also have available to them current information and training on AIDS/ARC infection control and transmissibility given their daily proximity to their clients.

**Recommendation 8:**

**Reliance on volunteers in the direct provision of support services should be reduced.**

Volunteers currently constitute the principal source of support, both practical and emotional, for persons with ARC or AIDS throughout the state. High volunteer-to-staff ratios provide for minimum supervision. The caregiving burden, exacerbated by inadequate supervision, can result in volunteer burnout. Some higher-level emotional needs cannot be accommodated even by the best trained and most experienced volunteers. As caseloads grow, the historical reliance on volunteers does not appear practical or feasible. Additional resources should be made available to increase direct service staffing in all areas of practical and psycho-social support to lessen reliance on informal sources of care.

**Recommendation 9:**

**Existing volunteer-to-staff ratios in AIDS support service agencies should be reduced.**

To provide paraprofessional and practical services effectively and to ensure that the changing needs of the AIDS/ARC client are routinely met, resources should be made available for staff to provide supervision and training to volunteer caregivers. Trained professionals should supervise and coordinate volunteer activities more closely than is currently possible in most areas where caseloads are growing and funding is far below needed levels. Expanded supervision should recognize the support needs of volunteers to manage stress and prevent volunteer burnout, a growing problem in many areas.

**Recommendation 10:**

**Staff of AIDS service agencies should have available a training program on the particular supportive service needs of minorities, IV drug users, women and children with AIDS/ARC.**

The continued expansion of AIDS/ARC in the minority and IVDU communities in California, and the emergence of women and children with ARC or AIDS is posing a considerable challenge to service agencies across the state. The state should support the development of a comprehensive program of training and follow-up technical assistance on the special aspects of the AIDS epidemic in these groups. The program should be made available to all agencies providing AIDS/ARC services with the goal of sensitizing providers and expanding supportive services for these groups.

**Recommendation 11:**

**Appropriate education and training on HIV infection should be made available to all health care, social service and allied professionals providing services to PWAs/PWARCs, seropositives and their families.**

The need for up-to-date information on AIDS/ARC is essential for all professionals serving this population. Allied health professionals and providers of social services along with clinical health care providers should have available to them multidisciplinary education and regular training on an array of topics and issues pertinent to their professional activities. Although the state Office of AIDS currently is funding some activities in this area, expanded training will not only enhance the provision of existing services but may also help encourage reticent providers to become involved in the care of persons with ARC or AIDS.

**Recommendation 12:**

**Each community should designate a "core" AIDS service agency as the focal point for delivering basic supportive services and for coordinating the delivery of other necessary services.**

Comprehensiveness, coordination and efficiency of services should be encouraged in all communities by identifying an entity as the core AIDS service agency. This entity

should provide basic supportive services (see Chapters Three and Four) and should serve as a participant in service planning for the AIDS service network. A primary goal of this identification should be to enhance service integration, avoid duplication and coordinate administrative policies concerning eligibility, documentation and case management throughout the AIDS service network. The network should involve public and private health care and social service providers, AIDS/ARC education and service agencies and other key individuals and organizations so as to facilitate a coordinated system of service delivery.

**Recommendation 13:**

**AIDS/ARC supportive services agencies should conduct outreach to identify and serve underserved individuals and groups.**

Statewide, AIDS service agencies are perceived as principally directed towards the gay male population, and cultural barriers have constrained the use of these services by other groups with supportive service needs. Agencies must begin vigorous and culturally sensitive outreach to identify AIDS, ARC and seropositive cases in the minority community, among women and children and among IV drug users. Services appropriate to the needs and sensibilities of these individuals should be developed and expanded. Outreach and education must occur in these communities where the epidemic is growing rapidly and where unmet supportive service needs are greatest and resources are traditionally the lowest.

**Recommendation 14:**

**Each community AIDS service agency should have staff identified for case management for IV drug users, women and children.**

IVDUs with AIDS, ARC or seropositivity require services from several disparate sectors which have not traditionally required close working relationships or cross-agency case management. As increasing number of IVDUs enter the AIDS/ARC service network, specially trained staff will be needed to integrate social support, health care and drug treatment services. The complexity of the service networks and the characteristics of the IVDU group requires an identifiable IVDU case manager in all agencies serving PWAs/PWARCs as their principal clients.

Similarly, the emergence of AIDS/ARC in California women and children will require AIDS agencies to deliver supportive services to women and to children and their families. Also needed will be effective management of women's and children's AIDS/ARC cases across a variety of agencies and organizations, many of which provide services exclusively to these groups and which are likely outside the experience of most AIDS agencies. Each AIDS service agency should identify a qualified case manager who is knowledgeable of and sensitive to women's health issues, service needs and service providers.

**Recommendation 15:**

**Agencies providing supportive services to persons with ARC or AIDS should recognize and respond to the support needs of family members.**

Partners, parents, siblings, friends and volunteers often provide the majority of support to PWAs/PWARCs. These individuals, who may be considered as members of a PWA's/PWARC's extended family, experience a variety of needs for support themselves. Agencies, particularly those providing psycho-social support, should be sensitive to the supportive service needs of family members and appropriate interventions should be developed. Continued reliance on family members for caregiving should be supported by a sensitive consideration of their needs.

**Recommendation 16:**

**Agencies serving persons with ARC, AIDS or seropositivity should use standardized intake assessments and service record forms.**

Effective case management is hampered by massive differences in intake and assessment procedures and in service documentation records. Service planning is made more speculative due to the absence of reliable service utilization and other information. Agencies serving HIV-infected persons in each community (and, ideally, statewide) should participate in the development of, and make use of, standardized client intake/assessment and service recording forms to ensure client confidentiality, to establish continuity of the intake processes and to facilitate case management of individuals using services provided by multiple agencies.



**Recommendation 17:**

**AIDS/ARC information and referral services should expand their capacities to respond to changing I&R needs.**

AIDS/ARC information and referral providers often encounter the need to educate clients about AIDS and to provide support and guidance to individuals at risk and the "worried well." These functions derive from the unique nature of HIV infection, and I&R agencies should develop an expanded concept of their role in the AIDS/ARC service network and should provide substantial emotional support training to volunteers and staff alike. The composite approach of I&R tied to support and counseling used by suicide prevention agencies may serve as a useful model.

**Recommendation 18:**

**County government agencies providing supportive services to PWAs/PWARCs should have coordinated operating policies and ongoing linkages at the policy and service delivery levels.**

County programs in health services, social services, substance abuse and mental health represent key elements of an effective AIDS/ARC service network. Services from each of these sources should be readily available to persons with ARC or AIDS and to seropositives. Coordination across these agencies should be encouraged to expedite care and to avoid unnecessary administrative and service duplication. Linkages with nonprofit community-based AIDS/ARC service agencies, agencies providing related services (substance abuse, housing, mental health, home health, hospice) should also be encouraged.

**Recommendation 19:**

**The role of members of minority communities in the AIDS/ARC service network should be expanded.**

Members of minority communities are currently underrepresented in the AIDS/ARC service network at the policy, administrative and service delivery levels. Providing culturally appropriate and effective services to the growing numbers of PWAs/PWARCs in the Black, Latino and Asian communities should involve staff and volunteers from these groups. Outreach to minority service providers and to minority communities, if carried

out sensitively, should be undertaken by existing AIDS/ARC agencies to elicit input on the range of service and education issues. We do not find a need for or recommend development of parallel, minority-specific service networks, but recognize an urgent need for greater roles for minorities in existing and developing AIDS/ARC service networks.

**Recommendation 20:**

**AIDS service agencies should incorporate PWAs, PWARCs and seropositives in policy-making and planning functions.**

Service user involvement is a key to effective service delivery and PWA/PWARC/seropositive representatives from each affected community (minorities, women, IVDU) should actively participate in program planning, evaluation and organizational policy-making in AIDS service agencies, both public and private.

**Recommendation 21:**

**The current approach to client confidentiality must be maintained and institutionalized.**

Policies ensuring the strict confidentiality of information concerning the care of PWAs/PWARCs and seropositives should be developed by the state, by each county and by every agency providing services to this population. Procedures for ensuring client confidentiality at the service delivery level should be developed by all agencies. Routine training on confidentiality should be mandatory for all AIDS service providers, both professional and volunteer. Confidentiality should be a key policy, too, in designing case management and client record-keeping programs and in the development or expansion of community AIDS/ARC service networks.

## **APPENDICES**

- APPENDIX A: MEMBERS OF THE STATEWIDE PROJECT ADVISORY COMMITTEE**
- APPENDIX B: ORGANIZATIONS INTERVIEWED FOR THE NEEDS ASSESSMENT**
- APPENDIX C: QUESTIONNAIRE USED IN GROUP DISCUSSIONS**
- APPENDIX D: SURVEY INSTRUMENT FOR 20-COUNTY PROVIDER SURVEY AND LIST OF COUNTIES**
- APPENDIX E: COMBINED DATA FROM 20-COUNTY SURVEY OF PROVIDERS**

APPENDIX

TABLE 1. SUMMARY OF THE DATA FOR THE FIRST EXPERIMENT

TABLE 2. SUMMARY OF THE DATA FOR THE SECOND EXPERIMENT

TABLE 3. SUMMARY OF THE DATA FOR THE THIRD EXPERIMENT

TABLE 4. SUMMARY OF THE DATA FOR THE FOURTH EXPERIMENT

TABLE 5. SUMMARY OF THE DATA FOR THE FIFTH EXPERIMENT

## APPENDIX A

### MEMBERS OF THE STATEWIDE PROJECT ADVISORY COMMITTEE

Rev. Carl Bean  
Minority AIDS Project  
Los Angeles

Pat Franks  
AIDS Resource Program, UCSF  
San Francisco

Dale Meyer  
Catholic Social Services  
San Francisco

Cliff Morrison  
California Nurses Association and  
AIDS Health Services Program, UCSF  
San Francisco

Chuck Novak  
Sacramento AIDS Foundation  
Sacramento

Miguel Ramirez  
San Francisco AIDS Foundation and  
Latino Coalition for AIDS Education and Action  
San Francisco

Philip Reiff, M.D.  
Castro Medical Clinic and  
San Francisco Department of Public Health  
San Francisco

Yolanda Ronquillo  
Latino AIDS Education Project  
San Francisco

Ron Rose, PWA  
and Tom West  
Aid for AIDS  
Los Angeles

Paul Shearer  
Garden Sullivan Hospital  
San Francisco

Gary Starlipper  
PWA  
San Francisco

Sala Udin  
Multicultural Prevention and  
Resource Center  
San Francisco

Ona Rita Yufe  
San Diego AIDS Project  
San Diego

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## **APPENDIX B**

### **ORGANIZATIONS INTERVIEWED FOR THE NEEDS ASSESSMENT**

#### **FRESNO**

Central Valley AIDS Team  
Valley Medical Center  
Department of Public Health, Fresno County  
California Physician Resources Network  
St. Agnes Hospital  
San Joaquin Valley Health Consortium  
Psychotherapist in Private Practice  
Person with AIDS  
Caregiver/Family Member

#### **LOS ANGELES**

Aid for AIDS  
Shanti Foundation  
Children's Hospital of Los Angeles  
Minority AIDS Project  
AIDS Program Office, Department of Health Services, Los Angeles County  
AIDS Project Los Angeles  
Hollywood Community Hospital  
Being Alive  
AIDS Outpatient Clinic, County-USC Hospital  
Hospital Home Health Care Agency of California  
El Centro Human Services Corporation  
Women's AIDS Project  
Community Substance Abuse Services, Los Angeles County  
Gay and Lesbian Community Service Center  
Persons with ARC  
Persons with AIDS

#### **RIVERSIDE**

Desert AIDS Project  
Department of Health, Riverside County  
Hemet Hospice  
VNA of the Inland Counties  
Inland Counties AIDS Project



THE HISTORY OF THE  
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## **SACRAMENTO**

Sacramento AIDS Foundation  
Aquarian Effort  
University of California, Davis Medical Center  
Sutter Memorial Hospital/Hospice  
Transitional Living and Community Support  
Department of Social Services, Sacramento County  
Department of Public Health, Sacramento County  
California Hemophilia Council  
Visiting Nurses Association of Sacramento  
Metropolitan Community Church  
Psychotherapists in Private Practice  
Physicians in Private Practice  
Persons with ARC  
Persons with AIDS  
Caregivers/Family Members

## **SAN FRANCISCO**

San Francisco AIDS Foundation  
Shanti Project  
Hospice of San Francisco  
Catholic Charities of San Francisco  
Latino AIDS Education Project  
San Francisco General Hospital  
Pacific Presbyterian Medical Center  
Department of Public Health, San Francisco County  
UCSF AIDS Resource Program  
Latino Coalition for AIDS Education and Action  
Garden Sullivan Hospital  
Community Substance Abuse Services, San Francisco County  
San Francisco Women's AIDS Network  
Franklin Hospital  
Physicians in Private Practice  
Persons with ARC  
Persons with AIDS

## **SANTA CLARA**

Aris Project  
Holy Trinity Community Church  
Imperial AIDS Foundation  
Department of Public Health, Santa Clara County  
Department of Social Services, Santa Clara County  
Santa Clara Valley Medical Center  
Catholic Charities  
Bay Area Municipal Elections Commission  
Persons with ARC  
Persons with AIDS



**APPENDIX C**  
**QUESTIONNAIRE USED IN GROUP DISCUSSIONS**

THE UNIVERSITY OF CHICAGO  
LIBRARY

**THE URSA INSTITUTE**

**ASSESSMENT OF SUPPORTIVE SERVICE NEEDS  
FOR PERSONS WITH AIDS OR ARC**

**FOCUS GROUP PARTICIPANT PROFILE**

Thank you for participating in our study which will help us understand the kinds of services needed by persons with AIDS or ARC. Your answers to the following questions would be most helpful. Please remember that all information you provide is **COMPLETELY CONFIDENTIAL**.

First are some questions about yourself:

1. YOUR SEX: \_\_\_\_\_ MALE  
\_\_\_\_\_ FEMALE
  2. YOUR AGE: \_\_\_\_\_ YEARS
  3. YOUR RACE/ETHNICITY: \_\_\_\_\_ ASIAN  
\_\_\_\_\_ BLACK  
\_\_\_\_\_ CAUCASIAN  
\_\_\_\_\_ LATINO  
\_\_\_\_\_ OTHER  
(PLEASE SPECIFY: \_\_\_\_\_)
  4. LAST GRADE COMPLETED IN SCHOOL: \_\_\_\_\_ GRADE
  5. HAVE YOU BEEN DIAGNOSED WITH AIDS? \_\_\_\_\_ NO  
\_\_\_\_\_ YES
- IF YES, MONTH AND YEAR OF DIAGNOSIS: \_\_\_\_\_ MONTH \_\_\_\_\_ YEAR

6. HAVE YOU BEEN DIAGNOSED WITH ARC? \_\_\_\_\_ NO

\_\_\_\_\_ YES

IF YES, MONTH AND YEAR OF DIAGNOSIS:

\_\_\_\_\_ MONTH, \_\_\_\_\_ YEAR

7. WHAT KIND OF HEALTH INSURANCE  
DO YOU CURRENTLY HAVE:

\_\_\_\_\_ NO INSURANCE

\_\_\_\_\_ PRIVATE POLICY  
(LIKE BLUE CROSS, KAISER ETC.)

\_\_\_\_\_ MEDI-CAL

\_\_\_\_\_ OTHER  
(PLEASE SPECIFY: \_\_\_\_\_)

The next questions are about your need for services.

8. WHICH OF THE FOLLOWING SERVICES ARE MOST IMPORTANT TO YOU  
NOW? CIRCLE EACH FROM 1 TO 5 WITH 1 BEING NO NEED FOR SERVICE  
AND 5 BEING A VERY IMPORTANT NEED.

	NO NEED		MEDIUM NEED		VERY IMPORTANT NEED
	1	2	3	4	5
AFFORDABLE HOUSING	1	2	3	4	5
HELP FINDING HOUSING	1	2	3	4	5
TRANSPORTATION	1	2	3	4	5
LEGAL HELP	1	2	3	4	5
HELP WITH CLEANING, COOKING AT HOME	1	2	3	4	5
HELP WITH MEDICATIONS	1	2	3	4	5
COUNSELING	1	2	3	4	5
EMOTIONAL HELP FOR FAMILY OR LOVER	1	2	3	4	5
HELP WITH A DRUG OR ALCOHOL PROBLEM	1	2	3	4	5



	<u>NO NEED</u>		<u>MEDIUM NEED</u>		<u>VERY IMPORTANT NEED</u>
HELP FINDING SERVICES OR GETTING GOVERNMENT BENEFITS (SSI, MEDI-CAL, DISABILITY, ETC.)	1	2	3	4	5
OTHER (SPECIFY: _____)	1	2	3	4	5

9. HOW EASY OR HARD HAS IT BEEN TO GET THESE SERVICES WHEN YOU NEED THEM? CIRCLE EACH FROM 1 TO 5 WITH 1 BEING VERY EASY AND 5 BEING VERY DIFFICULT. CIRCLE 9 IF YOU HAVE NOT TRIED TO USE A SERVICE.

	VERY EASY		MEDIUM		VERY DIFFICULT	HAVE NOT TRIED TO USE
AFFORDABLE HOUSING	1	2	3	4	5	9
HELP FINDING HOUSING	1	2	3	4	5	9
TRANSPORTATION	1	2	3	4	5	9
LEGAL HELP	1	2	3	4	5	9
HELP WITH CLEANING, COOKING AT HOME	1	2	3	4	5	9
HELP WITH MEDICATIONS	1	2	3	4	5	9
COUNSELING	1	2	3	4	5	9
EMOTIONAL HELP FOR FAMILY OR LOVER	1	2	3	4	5	9
HELP WITH A DRUG OR ALCOHOL PROBLEM	1	2	3	4	5	9
HELP FINDING SERVICES OR GETTING GOVERNMENT BENEFITS (SSI, MEDI-CAL, DISABILITY, ETC.)	1	2	3	4	5	9
OTHER (SPECIFY: _____)	1	2	3	4	5	9

10. WHAT HAVE BEEN THE BIGGEST PROBLEMS IN GETTING SERVICES WHEN YOU NEEDED THEM? CHECK ALL THAT APPLY.

DIDN'T KNOW WHERE TO LOOK FOR  
THE SERVICE

\_\_\_\_\_

COULDN'T AFFORD THE COST OF  
THE SERVICE

\_\_\_\_\_

THE SERVICE WAS JUST NOT AVAILABLE

\_\_\_\_\_

I WAS NOT ELIGIBLE FOR THE SERVICE

\_\_\_\_\_

I DID NOT FEEL WELCOME WHERE SERVICE  
WAS OFFERED

\_\_\_\_\_

TRANSPORTATION PROBLEM - COULDN'T  
GET THERE

\_\_\_\_\_

THANK YOU FOR YOUR HELP, OUR GROUP WILL BEGIN IN JUST A FEW  
MINUTES.

**APPENDIX D**

**SURVEY INSTRUMENT FOR 20-COUNTY PROVIDER SURVEY  
AND LIST OF COUNTIES**

1954年10月

1954年10月1日 星期日 晴

## STATEWIDE AIDS/ARC NEEDS ASSESSMENT QUESTIONNAIRE

1. Based on your experience and professional training, how likely is it that the current and projected numbers of people with AIDS or ARC in your county would need the following services?

	Very likely	Somewhat likely	Not likely
Affordable Housing	1	2	3
Transportation	1	2	3
Legal Assistance	1	2	3
Help with Cleaning or Cooking at Home	1	2	3
Help with Medications	1	2	3
Psychological Counseling	1	2	3
Emotional Support Groups	1	2	3
Emotional Help for Loved Ones	1	2	3
Skilled Nursing Care	1	2	3
Intermediate Nursing Care	1	2	3
Hospice Services	1	2	3
Help with a Drug or Alcohol Problem	1	2	3
Case Management	1	2	3
Help with Finding Services or Getting Government Benefits	1	2	3
Other ( _____ )	1	2	3

2. How would you rate the capacity of your county's public and private human service agencies to meet the anticipated level of need for supportive services by people with AIDS or ARC?

	Could Meet Now	Will Need Some New Resources	Will Need Many New Resources	Don't Know
Affordable Housing	1	2	3	4
Transportation	1	2	3	4
Legal Assistance	1	2	3	4
Help with Cleaning or Cooking at Home	1	2	3	4
Help with Medications	1	2	3	4
Psychological Counseling	1	2	3	4
Emotional Support Groups	1	2	3	4
Emotional Help for Loved Ones	1	2	3	4
Skilled Nursing Care	1	2	3	4
Intermediate Nursing Care	1	2	3	4
Hospice Services	1	2	3	4
Help with a Drug or Alcohol Problem	1	2	3	4
Case Management	1	2	3	4
Help with Finding Services or Getting Government Benefits	1	2	3	4
Other (_____)	1	2	3	4

3. In your opinion, how have the private and public agencies in your county responded to the supportive service needs of people with AIDS and ARC who have already been diagnosed?

- ☐ All of their service needs have been met.
- ☐ Most of their service needs have been met.
- ☐ Some of their service needs have been met.
- ☐ Few of their service needs have been met.
- ☐ None of their service needs have been met.

4. Are there particular supportive services that have been especially difficult for people with AIDS or ARC in your county to obtain? If so, please describe these services briefly and indicate if you think these problems are likely to continue.

5. Please rank the following types of human service organizations according to your perceptions of their overall abilities to meet the supportive service needs of people with AIDS and ARC in your county. The ranking scale is: 1 = very capable; 2 = somewhat capable; 3 = not very capable; 4 = incapable.

- ☐ private health care providers
- ☐ private social service agencies
- ☐ public health care providers
- ☐ public social service agencies
- ☐ private mental health providers
- ☐ public mental health providers
- ☐ private substance abuse treatment providers
- ☐ public substance abuse treatment providers



6. If you believe that people diagnosed with AIDS and ARC in your county will need services other than those identified in this questionnaire, please describe those service needs. Please include your assessment of the implications of any changes predicted in the demographic characteristics of AIDS/ARC cases in your county.

7. We need to know just a few things about you.

Is your agency a

- ☐ health care provider
- ☐ social service provider
- ☐ provider of both kinds of services
- ☐ mental health provider?

Is your agency ☐ public or ☐ private?

Name \_\_\_\_\_  
Agency \_\_\_\_\_  
Telephone \_\_\_\_\_

**THANK YOU FOR YOUR HELP**

**APPENDIX D (continued)**

**LIST OF COUNTIES INCLUDED IN THE  
NEEDS ASSESSMENT SURVEY**

**Alameda**

**Butte**

**Contra Costa**

**El Dorado**

**Inyo**

**Marin**

**Merced**

**Monetary**

**Orange**

**Placer**

**San Benito**

**San Bernadino**

**San Diego**

**San Joaquin**

**San Luis Obispo**

**Santa Barbara**

**Solano**

**Stanislaus**

**Trinity**

**Yuba**

1917  
1918  
1919

1920

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1943

1944

1945

**APPENDIX E**  
**COMBINED DATA FROM 20-COUNTY SURVEY OF PROVIDERS**



**LIKELIHOOD OF SUPPORTIVE SERVICE NEED  
AMONG PWAs/PARCs**

**All Counties (N=47)**

Supportive Service	Likelihood of Need		
	Very Likely	Somewhat	Not Likely
Emotional Support Groups	91.3	4.3	4.3
Psychological Counseling	87.0	8.7	4.3
Help with Cooking or Cleaning	80.4	15.2	4.3
Skilled Nursing Care	80.4	13.0	6.5
Help with Finding Services	78.3	17.4	4.3
Emotional Help for Loved Ones	76.1	19.6	4.3
Hospice Services	71.7	21.7	6.5
Intermediate Nursing Care	69.6	21.7	8.7
Transportation	67.4	26.1	6.5
Affordable Housing	65.2	26.1	8.7
Case Management	63.6	31.8	4.5
Help with Medications	54.5	38.6	6.8
Legal Assistance	46.7	40.0	13.3
Substance Abuse Treatment	37.0	50.0	13.0

**LIKELIHOOD OF SUPPORTIVE SERVICE NEED  
AMONG PWAs/PWARCs**

**Large Counties (N=9)**

Supportive Service	Likelihood of Need		
	Very Likely	Somewhat	Not Likely
Emotional Support Groups	100.0	0.0	0.0
Psychological Counseling	100.0	0.0	0.0
Skilled Nursing Care	100.0	0.0	0.0
Help with Finding Services	100.0	0.0	0.0
Emotional Help for Loved Ones	100.0	0.0	0.0
Intermediate Nursing Care	100.0	0.0	0.0
Hospice Services	88.9	11.1	0.0
Legal Assistance	88.9	11.1	0.0
Help with Cooking or Cleaning	88.9	11.1	0.0
Transportation	88.9	11.1	0.0
Affordable Housing	88.9	11.1	0.0
Case Management	77.8	22.2	0.0
Help with Medications	77.8	22.2	0.0
Substance Abuse Treatment	55.6	44.4	0.0

**LIKELIHOOD OF SUPPORTIVE SERVICE NEED  
AMONG PWAs/PWARCs**

**Medium-Sized Counties (N=29)**

Supportive Service	Likelihood of Need		
	Very Likely	Somewhat	Not Likely
Emotional Support Groups	92.9	7.1	0.0
Psychological Counseling	85.7	14.3	0.0
Skilled Nursing Care	82.1	14.3	3.6
Help with Cooking or Cleaning	78.6	21.4	0.0
Help with Finding Services	78.6	21.4	0.0
Emotional Help for Loved Ones	78.6	21.4	0.0
Hospice Services	67.9	28.6	3.6
Transportation	67.9	28.6	3.6
Affordable Housing	67.9	28.6	3.6
Intermediate Nursing Care	64.3	28.6	7.1
Case Management	60.7	39.3	0.0
Legal Assistance	39.3	50.0	10.7
Help with Medications	38.5	57.7	3.8
Substance Abuse Treatment	25.0	60.7	14.3

**LIKELIHOOD OF SUPPORTIVE SERVICE NEED  
AMONG PWAs/PWARCs**

**Small Counties (N=9)**

Supportive Service	Likelihood of Need		
	Very Likely	Somewhat	Not Likely
Emotional Support Groups	77.8	0.0	22.2
Help with Medications	77.8	0.0	22.2
Psychological Counseling	77.8	0.0	22.2
Help with Cooking or Cleaning	77.8	0.0	22.2
Hospice Services	66.7	11.1	22.2
Case Management	57.1	14.3	28.6
Substance Abuse Treatment	55.6	22.2	22.2
Skilled Nursing Care	55.6	22.2	22.2
Intermediate Nursing Care	55.6	22.2	22.2
Help with Finding Services	55.6	22.2	22.2
Emotional Help for Loved Ones	44.4	33.3	22.2
Transportation	44.4	33.3	22.2
Affordable Housing	33.3	33.3	33.3
Legal Assistance	25.0	37.5	37.5



## CAPABILITY TO MEET SUPPORTIVE SERVICE NEEDS OF PWAs/PWARCs

All Counties (N=47)

Supportive Service	Could Meet Now	Will Need Some New Resources	Will Need Many New Resources	Don't Know
Emotional Support Groups	32.6	47.8	13.0	6.5
Emotional Help for Loved Ones	32.6	47.8	13.0	6.5
Substance Abuse Treatment	32.6	41.3	19.6	6.5
Hospice Services	30.4	37.0	28.3	4.3
Psychological Counseling	19.6	52.2	23.9	4.3
Skilled Nursing Care	17.4	26.1	52.2	4.3
Help with Medications	15.6	53.3	22.2	8.9
Help with Cooking or Cleaning	13.3	48.9	33.3	4.4
Legal Assistance	13.0	58.7	19.6	8.7
Help with Finding Services	13.0	54.3	26.1	6.5
Case Management	6.7	62.2	22.2	8.9
Transportation	6.7	57.8	28.9	6.7
Affordable Housing	2.2	28.9	62.2	6.7
Intermediate Nursing Care	2.2	37.8	55.6	4.4

## CAPABILITY TO MEET SUPPORTIVE SERVICE NEEDS OF PWAs/PWARCs

Large Counties (N=9)

Supportive Service	Could Meet Now	Will Need Some New Resources	Will Need Many New Resources	Don't Know
Help with Finding Services	33.3	33.3	33.3	0.0
Emotional Support Groups	22.2	44.4	33.3	0.0
Help with Medications	22.2	33.3	33.3	11.1
Substance Abuse Treatment	22.2	44.4	33.3	0.0
Transportation	12.5	50.0	25.0	12.5
Hospice Services	11.1	44.4	44.4	0.0
Emotional Help for Loved Ones	11.1	66.7	22.2	0.0
Psychological Counseling	11.1	55.6	33.3	0.0
Help with Cooking or Cleaning	11.1	55.6	33.3	0.0
Legal Assistance	11.1	44.4	33.3	11.1
Case Management	0.0	77.8	22.2	0.0
Affordable Housing	0.0	44.4	44.4	11.1
Skilled Nursing Care	0.0	22.2	77.8	0.0
Intermediate Nursing Care	0.0	22.2	77.8	0.0

# **CAPABILITY TO MEET SUPPORTIVE SERVICE NEEDS OF PWAs/PWARCs**

## **Medium-Sized Counties (N=29)**

<u>Supportive Service</u>	<u>Could Meet Now</u>	<u>Will Need Some New Resources</u>	<u>Will Need Many New Resources</u>	<u>Don't Know</u>
Emotional Help for Loved Ones	46.4	39.3	10.7	3.6
Emotional Support Groups	42.9	42.9	14.3	0.0
Hospice Services	39.3	35.7	25.0	0.0
Substance Abuse Treatment	35.7	42.9	17.9	3.6
Psychological Counseling	25.0	53.6	21.4	0.0
Skilled Nursing Care	21.4	25.0	53.6	0.0
Help with Cooking or Cleaning	18.5	48.1	33.3	0.0
Legal Assistance	17.9	67.9	14.3	0.0
Help with Medications	11.1	70.4	14.8	3.7
Case Management	10.7	57.1	28.6	3.6
Help with Finding Services	7.1	64.3	28.6	0.0
Transportation	3.6	64.3	32.1	0.0
Affordable Housing	3.6	21.4	75.0	0.0
Intermediate Nursing Care	0.0	21.4	75.0	0.0

# **CAPABILITY TO MEET SUPPORTIVE SERVICE NEEDS OF PWAs/PWARCs**

## **Small Counties (N=9)**

<u>Supportive Service</u>	<u>Could Meet Now</u>	<u>Will Need Some New Resources</u>	<u>Will Need Many New Resources</u>	<u>Don't Know</u>
Emotional Support Groups	44.4	22.2	22.2	22.2
Substance Abuse Treatment	33.3	33.3	11.1	22.2
Hospice Services	22.2	33.3	22.2	22.2
Skilled Nursing Care	22.2	33.3	22.2	22.2
Help with Medications	22.2	22.2	33.3	22.2
Intermediate Nursing Care	12.5	50.0	12.5	25.0
Emotional Help for Loved Ones	11.1	55.6	11.1	22.2
Psychological Counseling	11.1	44.4	22.2	22.2
Help with Finding Services	11.1	44.4	11.1	22.2
Transportation	11.1	44.4	22.2	22.2
Case Management	0.0	62.5	0.0	37.5
Help with Cooking or Cleaning	0.0	44.4	33.3	22.2
Legal Assistance	0.0	44.4	22.2	22.2
Affordable Housing	0.0	37.5	37.5	25.0

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